

“AT HOME, I’M CLARK KENT. AT CAMP, I’M SUPERMAN”: OUTCOMES AND  
PROCESSES OF A CAMP FOR YOUTH WITH HIV/AIDS

A Dissertation

by

ANN GILLARD

Submitted to the Office of Graduate Studies of  
Texas A&M University  
in partial fulfillment of the requirements for the degree of  
DOCTOR OF PHILOSOPHY

May 2009

Major Subject: Recreation, Park, and Tourism Sciences

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## ABSTRACT

“At Home, I’m Clark Kent. At Camp, I’m Superman”: Outcomes and Processes of a  
Camp for Youth with HIV/AIDS. (May 2009)

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Understanding how inputs influence program outcomes is a key step in designing and implementing quality youth programs to support positive development. While developmental processes are assumed to be universal for all populations, youth who face additional challenges in their development (such as those with chronic illness) may have unique experiences in youth programs.

Using Developmental Systems Theory as the guiding theory, the purpose of this study was to understand the developmental context for youth with HIV/AIDS at a barrier-free camp. This study addressed the specific questions: (1) what were the developmental outcomes experienced by youth as a result of attending camp; and (2) what were the processes that facilitated youth development at camp? An interpretive case study employing observations, focus groups, and interviews was used to investigate the research questions.

Findings show that camp plays a major developmental role in the lives of youth with HIV/AIDS. Four thematic outcomes of camp emerged: (1) experiencing caring people, (2) developing a sense of belonging, (3) feeling reprieve and recreation, and (4)

increasing knowledge, attitudes, and skills. The four themes were strongly linked together, being nested within each other in a temporal order. When campers experienced caring people, they had a sense of belonging. These two relationship-based outcomes opened a space for feelings of reprieve (from responsibilities and stigma at home) and recreation (to engage in fun activities) at camp, and this relaxed space provided an opportunity for increasing knowledge, attitudes, and skills.

Processes that contributed most to the campers' experiences of caring people were long-term relationships, outside of camp support, exposure and storytelling, and Teen Talk (an educational workshop). Processes contributing to campers' development of a sense of belonging were acculturation into the camp; an educational activity called Teen Talk, medication taking, grieving, aging out of camp, and storytelling. Processes contributing to campers' experiences of reprieve and recreation were camp activities (including Teen Talk); planning for the needs of campers, accessibility, and freedom from worry. Processes contributing to campers' development of knowledge, attitudes, and skills were education through Teen Talk, and non-Teen Talk education. Implications for theory, research, and practice are discussed.

## DEDICATION

This dissertation is dedicated to the campers, volunteers, and staff of Camp Hope, UniversalTeens, AIDS Foundation Houston, and Camp For All. It is through your eternal optimism, kind hearts, hard work, and visions of a better world for all that you have touched and improved so many lives, including mine.

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Special thanks go to Dr. Clif Watts for his major role in the development and early stages of this study, and for his efforts in connecting me to Camp For All. The conceptualization, need for the study, and relationships between the positive youth development literature and the disability literature were directly influenced by him.

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## NOMENCLATURE

ACA	American Camp Association
AIDS	Acquired Immune Deficiency Syndrome
CD	Camp Director
CDC	Centers for Disease Control and Prevention
CFA	Camp For All
CH	Camp Hope
CIT	Counselor-in-Training
DST	Developmental Systems Theory
EST	Ecological Systems Theory
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HRQOL	Health-Related Quality of Life
OST	Out-of-School Time
PHD	Positive Human Development
PYD	Positive Youth Development
TT	Teen Talk
UT	UniversalTeens



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## CHAPTER I

### INTRODUCTION

There is a pressing need to understand how developmental outcomes occur through participation in out-of-school time (OST) programs (Baldwin, Caldwell, & Witt, 2005; Catalano, Berglund, Ryan, Lonczak, & Hawkins, 2002; Fredricks & Eccles, 2006). The need is especially acute for understanding how OST programs can support youth who face additional challenges in their developmental processes, such as those with chronic illnesses and disabilities (Britto, 2006; Dodge & Pettit, 2003; Sawyer, Drew, Yeo, & Britto, 2007); often, the assumption by researchers is that developmental processes are universal when in fact they might not be. Additionally, it is important to understand how different OST program contextual factors (such as activity leaders and organizational goals) may influence various outcomes for youth throughout their development (Eccles & Gootman, 2002; Mahoney, Eccles, & Larson, 2004; Roth & Brooks-Gunn, 2003). Stakeholders such as program administrators and staff, funding agencies, parents, and youth are interested in learning how processes found within OST structures and practices may provide youth with opportunities to experience desirable developmental outcomes (e.g., Benson & Pittman, 2001; Greenberg et al., 2003).

A useful way to understand processes within OST structures and practices and their influence on youth is through Developmental Systems Theory (DST).

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This dissertation follows the style of *Journal of Leisure Research*.

Developmental Systems Theory is a meso-theory that proposes there are multiple levels of influence involved in individuals' lives (such as biology, family, and social policies) that must be appropriately aligned with ontogeny in order for individual potential to become fully expressed (Lerner, 2006). In this framework, the focus is on the fit between a person and his or her context. Contexts with good fit are those that are developmental-stage appropriate, interesting, and engaging, and also provide support via interactions with caring adults and peers, and opportunities for competence-building. Contexts with these qualities are those that are believed to be best situated for optimal youth development (Eccles & Gootman, 2002; Roth, Brooks-Gunn, Murray, & Foster, 1998).

More proximal contexts (such as family or the close relationships formed in the collaborative living environment of a camp) are thought to have stronger influences on youth than more distal contexts such as economic or education policies (Lerner & Galambos, 1998). Important elements within youths' ecologies include the emotional, motivational, and strategic support of adults and peers, as well as opportunities for skill development and new responsibilities (Eccles & Gootman, 2002; Roth et al., 1998). The fundamental premise of DST is that supports and opportunities in the ecologies of youth must be a developmentally appropriate fit to individual young people.

Certain types of practices within programs have been shown to provide such fit and to enhance youth development, particularly through youth-adult relationships. For example, in a literature review of OST programs, Grossman and Bulle (2006) discussed several factors that foster youth-adult relationships. On the adult-level, these included opportunities for informal socializing, being responsive to youth's needs and desires,

good teaching skills, shared interests and characteristics, and respect. On the staff level, factors included judicious hiring, and training and supervision. On the program level, types of activities were found to be less important than the relationships within the activities. Additionally, an organizational culture of making time to socialize and interact with youth was found to support positive youth-adult relationships. Specifically, positive staff-youth relationships have been found to be predictive of better prosocial school outcomes, and decreased disciplinary outcomes (Anderson-Butcher, Cash, Saltzburg, Midle, & Pace, 2004).

The relationships between youth and adults have been examined in other studies as well. For example, DuBois et al. (2002) conducted a meta-analysis of mentoring program evaluations, and suggested that program fidelity was important to ensuring benefits of participation, and that there appeared to be a profile of ‘best practices’ that were related to program effectiveness. These practices included ongoing training, structured activities for mentors and youth, high frequency of contact, appropriate matching, and overall adequate support and structure for mentoring relationships.

Structuring program practices for optimal outcomes is a topic of interest to youth development researchers (e.g., Carruthers, 2006; Henderson, Bialeschki et al., 2007; Whitlock, 2006). In a study on competence and program structure, Mahoney, Parente, and Lord (2007) found that the level of OST program engagement was positively linked to youth’s effectance motivation and social competence. Also observed in this study were connections between youth’s engagement in the program and program quality, which consisted of organization, social climate, and a skill-building emphasis; high

quality programs were highly engaging. Still, calls for research suggest a need for even more understanding of *how* outcomes are achieved in OST programs (e.g. Eccles, Barber, Stone, & Hunt, 2003; Larson, Hansen, & Moneta, 2006).

Program-level factors such as staffing, relationship support, and engaging activities are found in a variety of OST contexts. For example, summer camp is designed to foster positive relationships and competence-building opportunities, and offers supports and opportunities for youth to initiate and engage in behaviors that aid in the transition to adulthood. Research on the outcomes of camp participation demonstrates that camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality (Thurber, Scanlin, Scheuler, & Henderson, 2007a). A few studies have explored supports and opportunities within the camp setting, such as autonomy support (Hill & Sibthorp, 2006), camp management practices (Henderson, Powell, & Scanlin, 2005; Moorman, 1998), and camp staff factors (such as training and motivation) (DeGraaf & Neal, 1993; Henderson, Bialeschki et al., 2007). However, more research is needed to better relate camps' program theories, goals, and program components to outcomes for campers.

Camp has long been an opportunity for youth to become empowered and build character, skills, and relationships. Recognizing the opportunities for such outcomes that are inherent in camp settings, professionals serving youth with disabilities have advocated that this population stands to greatly benefit from this experience (e.g., Bluebond-Langner, Perkel, & Goertzel, 1991; Brown, 2005; McAuliffe-Fogarty, Ramsing, & Hill, 2007). Camps serving youth with disabilities attempt to provide these



youth with opportunities that many youth without disabilities experience in their daily lives. Camps for youth with disabilities tend to fall into one of two categories: 1) inclusive camps or those who serve youth with and without disabilities together within the same program; and 2) those that segregate youth with disabilities to focus on disability-specific needs and challenges. The goals of many of these latter types of camps is to provide youth with coping skills, education about their conditions, and a sense of belonging, as well as leisure and recreation activities in a barrier-free environment. Like other camps that use a positive youth development framework, camps for youth with disabilities aim to build assets in their campers. This framework is adopted despite the relative dearth of specific information about the developmental experiences and challenges faced by youth with disabilities in the youth development literature.

It is widely acknowledged that the ultimate goal of youth development is the emergence of fully functioning and engaged adults who are able to care for themselves and others while contributing to society (Pittman, Irby, Tolman, Yohalem, & Ferber, 2003). It is also widely acknowledged that the ultimate goal for youth with disabilities, especially those with chronic illness, is the same (e.g., Stam, Hartman, Deurloo, Groothoff, & Grootenhuys, 2006; Stewart, Stavness, King, Antle, & Law, 2006). Yet, the literature pertaining to positive youth development and disability appear to have different foci. Positive youth development literature tends to focus more on the developmental experiences of populations without disability, while much of the disability literature focuses on specific health-related outcomes while rarely taking into

account socio-ecological and developmental contexts of youth. This study aims to bridge this divide by exploring the experiences of youth with chronic illnesses (specifically HIV and AIDS) at camp using a positive youth development framework. For youth with chronic illness, positive youth development is thought to be more complex than for those who do not face such additional challenges; possibly suggesting a greater role of developmental supports and opportunities within the systems that these youth live.

### **Statement of the Problem**

More information is needed about how campers perceive the camp context as supportive of their needs (Henderson et al., 2007). Specifically, Henderson et al. suggest that “the benefits and contributions of the camp environment and campers’ experiences to the treatment milieu usually are not examined” (p. 763). While some empirical research exists on camps (e.g., Bialeschki, Henderson, & James, 2007; Garst & Bruce, 2003; Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007), few studies examine the features of the programmatic contexts of youth development (e.g., Anderson-Butcher et al., 2004; Fredricks & Eccles, 2005; Kahne et al., 2001). Based on a review of available literature, it appears that no studies have explored the developmental context to which youth with chronic illnesses are exposed during camp. Understanding how particular programmatic inputs optimize outcomes is a key step in the design and implementation of quality recreation and leisure programs that support youth development for those facing additional developmental challenges.

The importance of recreation and leisure experiences in people’s lives has been well-documented (Hutchinson, Loy, Kleiber, & Dattilo, 2003; Iso-Ahola, 1980; Kelly,

1996). Neulinger (1981) suggested that pure leisure consists of the combination of high levels of perceived freedom, intrinsic motivation, and internal locus of control to engage in the experience. Social relationships can support engagement in leisure activities (Kleiber, Wade, & Loucks-Atkinson, 2005), as can individual strategies related to the selection of activities, optimization of engagement, and compensation in the event of changing conditions (Caldwell & Baldwin, 2005). Employing these relationships and strategies in leisure services can serve as a buffer to the immediacies of stress, and a resource to sustain coping efforts, for self-restoration, and for personal transformation (Hutchinson & Kleiber, 2005).

Kleiber, Larson, and Csikszentmihalyi (1986) found that one particular group of people – adolescents - have reported greater freedom, intrinsic motivation, and positive affect in leisure activities than in productive activities (e.g. schoolwork or jobs) or maintenance activities (e.g., chores and personal care). Additionally, their participation in structured activities such as sports and arts was related to higher levels of concentration and challenge than all other activities. Well-documented links exist between participation in structured leisure activities during out-of-school time and adult educational attainment, occupation, income, self-esteem, ability to overcome adversity, political involvement, and physical health (Barber, Stone, & Eccles, 2005), psychological and behavioral functioning (Bartko & Eccles, 2003), and educational outcomes (Cooper & Valentine, 1999; Eccles et al., 2003).

However, research has shown that children with disabilities are less likely to participate in ordinary recreation and leisure activities (King et al., 2003). In the face of

chronic illness, youth may experience a loss of power and control; having successful experiences with leisure activities may alleviate some of these feelings, for within leisure are possibilities for self-determined action (Kelly, 1996). Still, it is critical to move beyond the link between participation and outcomes in order to understand the *components* of developmental contexts experienced by youth with chronic illness that can lead to desired developmental outcomes as a result of their camp participation.

### **Purpose and Research Questions**

The purpose of this study was to understand the developmental context for youth with chronic illness (HIV/AIDS) at a barrier-free camp, using Developmental Systems Theory as the guiding framework. Specifically, this study sought to answer the following research questions:

- (1) What are the developmental outcomes experienced by youth as a result of attending camp; and
- (2) What are the processes that facilitate youth development at camp?

The study used qualitative inquiry methods to gain an in-depth understanding of the interactions between campers and the camp context, and how these interactions shaped campers' development.

### **Significance of Study**

While studies have been conducted to better understand processes of positive youth development in OST, and some studies have addressed the experiences of youth with disabilities, these two research domains have not been integrated because research on youth with chronic illness typically does not specifically focus on positive youth

development. The contribution that the current study makes to the area of positive youth development is that it can help articulate how supports and opportunities found within the camp context relate to youth development outcomes, and delineate the processes and conditions that promote positive youth development in youth organizations such as camp.

Previous research on camps for youth with disabilities has not situated the outcomes achieved by campers into a larger developmental context, and more research is needed to clarify the connections between supports and opportunities for development, and developmental outcomes found within the camp context. Additionally, little research has been conducted on psychosocial intervention programs for youth with HIV and AIDS (e.g., Gosling, Burns, & Hirst, 2004; Naar-King et al., 2006), and only one descriptive study has been conducted on a camp for youth and their families who are living with HIV (Kmita, Baranska, & Niemiec, 2002). As young people with HIV/AIDS go through adolescence, it is important to understand the role that contexts such as camp can play in their development. This work supports administrators and staff of youth-serving organizations in their efforts to optimize outcomes for young people. The results of this study should help

- discover patterns in camper experiences, and what influence these patterns;
- identify connections between what programs do and what outcomes occur;
- inform program staff and administrators regarding ways to structure experiences for optimal youth development; and

- provide information that will facilitate the development and implementation of strategies to attain optimal youth development outcomes.

## CHAPTER II

### LITERATURE REVIEW

The following is a discussion of research related to the topics of youth development outcomes and processes at camps, and youth with HIV and AIDS. The aim of this literature review is to provide a theoretical framework in which to situate this study, and to understand the extent of existing knowledge about this topic. In keeping with this study's use of grounded theory for data analysis, the reviewed literature provide one of the bases for the "inductive and deductive interplay centered on the data offered by participants," (McGhee, Marland, & Atkinson, 2007, p. 341). As Strauss and Corbin (1998) suggest, reviewing literature before collecting and analyzing data accomplished the goals of stimulating theoretical sensitivity and questions, providing a secondary source of data and supplementary validity, as well as directing theoretical sampling.

The topics included in this section are: Developmental Systems Theory, positive youth development concepts (including supports and opportunities), research related to camps, camps for youth with disabilities, youth with chronic illness, and youth with HIV and AIDS. Major findings are discussed, and gaps in the literature identified to provide conceptual clarity of these key topics (Cutcliffe, 2000).

#### **Developmental Systems Theory**

Developmental Systems Theory (DST) was the guiding framework for this study. This theory is complementary to Bronfenbrenner's Ecological Systems Theory (EST)

(1979, 1998), which proposes that people exist within different systems ranging from proximal to distal in relation to the individual. What differentiates DST from EST is that DST has a temporal aspect. Generally, DST further suggests that characteristics at any level of the developmental system may promote adaptive outcomes in the face of challenges, and the focus is on the fit between people and their contexts or environments; positive development is most likely when there is a good fit between individuals and the assets that support their development (Lerner, 2005). Relations between people and their contexts are seen as developmentally adaptive, and all people have the potential to positively develop over the course of their lives (Lerner, 2006). Lerner (2006, p. 43) further explains that

Such mutually influential person ↔ context relations occur when the strengths of individuals are aligned with those resources present in the ecology of human development that maximize the probability that individual strengths are instantiated as positive functioning or healthy developmental outcomes. These resources may be termed “developmental assets,” and a key idea with the PHD [positive human development] perspective is that individuals are embedded in contexts (e.g. families, schools, and communities) that possess such assets. Accordingly, within the PHD perspective, as well as within developmental systems models that give rise to this view of human development, the ubiquity of both human strengths and contextual developmental assets means that both individuals and their ecologies are active contributors to the developmental process, and to the possible promotion of healthy human development.



More proximal contexts such as family or neighborhoods are thought to have stronger influence on youth than do more distal contexts such as economic or education policies (Lerner & Galambos, 1998). These proximal processes are akin to the notion of supports and opportunities. Important elements within youth's ecologies include the emotional, motivational, and strategic support of adults and peers, as well as opportunities for skill development and new responsibilities (Eccles & Gootman, 2002; Roth et al., 1998). These supports and opportunities must be a developmentally appropriate fit to individual young people. For example, Lerner and Galambos (1998) suggest that there are three individual factors (age, expectations, and behavior) and three contextual factors (influences from peers, parents, and neighborhood) associated with the actualization of risk behaviors such as substance abuse, unsafe sex, violence, and school failure.

In much of positive youth development research, DST is the meso-theory on which assumptions about the efficacy of youth programs are based. Yet rarely is DST explicitly specified as the guiding theory for studies seeking to identify outcomes of participation in youth programs (exceptions include work by Lerner, Eccles, and their colleagues as discussed above). Still, calls have been made for further clarification of developmental systems processes, especially within youth settings (Lerner, Freund, De Stefanis, & Habermas, 2001; Mahoney et al., 2004; Pianta, 2001).

### **Positive Youth Development**

Positive youth development occurs when opportunities for positive change within the lifespan align with contextual assets that have the potential to foster positive change

or development (Lerner, Lerner et al., 2005). The positive youth development approach is more than simply preventing problems from occurring, or focusing on youth's resilience to negative life events; it assumes that helping youth to achieve their full potential is the best way to prevent them from experiencing problems, and becoming a drain on the resources of society. Such achievement can be called "thriving," that is, when a young person is "involved across time in such healthy, positive relations with his or her community and on the path to what Csikszentmihalyi and Rathunde (1998) described as 'idealized personhood' (an adult status marked by making culturally valued contributions to self, others, and institutions)" (Lerner, Dowling, & Anderson, 2003, p.173). Positive youth development can occur anywhere in any domain of a young person's life, including at school, with parents and family, with peers and friends, in OST programs, and within individuals.

A major tenet of positive youth development is that it is not enough for youth to be problem free, they must also be fully prepared for adulthood and fully engaged in society (Pittman et al., 2003). Protective factors that guard against negative influences (Witt & Caldwell, 2005), resiliency or coping mechanisms (Richardson, 2002), and internal and external assets that build strength (Scales, Benson, Leffert, & Blyth, 2000) form the foundation for preparing youth for adulthood, and ultimately their full engagement in society. This preparation necessitates supports and opportunities for positive youth development, such as those found through the involvement of youth in purposive, organized, OST programs (Eccles & Gootman, 2002; Gambone, Klem, & Connell, 2002).

Since the mid-1990s, youth organizations have generally taken the positive youth development approach to the design and implementation of their programs. Structures and practices in programs designed to target youth development are commonly referred to as program context, and are intentionally manipulated to promote certain outcomes related to the goals of the organization. Understanding program context is important to developing successful youth development programs and may also yield information about the complexities within developmental settings. Roth and Brooks-Gunn (2003) identified program goals, atmosphere, and activities as the primary defining characteristics of programs, and suggested that the relationships among these three characteristics vary by size of the program, intensity of engagement, sponsorship, and participant characteristics. Riggs and Greenberg (2004) described characteristics of after-school programs as often being heterogeneous in type and design (type of program, location, and climate), that duration and intensity of attendance impacts outcomes, and that different types of children (age, gender, cognitive characteristics) from different families and communities may be more or less likely to benefit from participation. Together, these studies suggest there are numerous variables at work within youth development contexts.

### **Supports and Opportunities**

During participation in OST programs, youth can be exposed to support for their developmental processes such as emotional regulation and peer relationship-building, as well as opportunities to explore emerging identities and interests. Together, *supports and opportunities* refer to program practices and situations that are intended by staff and

administrators to positively impact the developmental trajectories of youth. Supports and opportunities differ from programs and services (Witt & Caldwell, 2005, p. 243).

*Programs* are those endeavors that are intentionally planned to achieve certain outcomes for groups of youth (i.e. building social skills, preventing violence, etc.). *Services* are designed to help individual youth in need of assistance, such as with health care or counseling. Despite efforts to provide distinct definitions, there is significant overlap between these four ingredients of positive youth development contexts. This study will primarily focus on the supports and opportunities found within a camp program.

Different researchers and studies have proposed a variety of ways to group supports and opportunities (e.g. Benson, Scales, Hamilton, & Sesma, 2006; Gambone et al., 2002; Pittman, Diversi, & Ferber, 2002). The current study will use Roth, Brooks-Gunn, Murray, and Foster's (1998) distinction between supports and opportunities:

...young people need the opportunity for: (a) challenging and relevant chances for formal and informal instruction and training, including explorations, practice, and reflection as well as expression and creativity; and (b) new roles and responsibilities, including group membership, contribution and service, and part-time paid employment. The supports youth need include (a) ongoing contact with people and social networks that provide emotional support, such as friendships and nurturance; (b) motivational supports such as high expectations, standards, and boundaries; and (c) strategic supports, such as options assessment and planning, and access to resources (p. 427).

The program structures around which these supports and opportunities are made available are usually less defined than the developmental goals of the program. Eccles and Gootman (2002) attempted to delineate eight features of developmental settings: physical and psychological safety; clear and consistent structure and appropriate adult supervision; supportive relationships; opportunities to belong; positive social norms; support for efficacy and mattering; opportunities for skill building, and; integration of family, school, and community. The authors also noted that the term *features* refers to youth's *interactions* with the setting and processes that take place within the program setting; neither youth nor features exist independently.

The notion of supports and opportunities for development is closely aligned with Developmental Systems Theory. However, while research has been conducted that applied DST to genetics and physiological behaviors (e.g., Molenaar, Huizenga, & Nesselroade, 2003; Steinberg & Morris, 2001), less focus has been given to using DST as a framework for understanding processes that support youth development in out-of-school time settings.

### **Camp**

One particular setting of youth development is summer camp. The camp movement began in the 1860s with the goal to involve youth in the out-of-doors to build moral character and physical strength. Throughout camp's evolving history, there have been several specific goals for youth that camps have consistently strived to achieve, including health and physical fitness, identity development, values clarification, and

social skills. Today, the American Camp Association (ACA) estimates that over 11 million individuals go to one or more of over 12,000 camps each year (ACA, 2008a).

Several studies and evaluations have found that participation in camp has been associated with a number of outcomes for youth. For example, after participation in camp, improvements were found in measures of self-esteem and self-efficacy (Kiernan, Gormley, & MacLachlan, 2004; Readdick & Schaller, 2005), social competencies (Hanes, Rife, & Laguna, 2005; Thurber et al., 2007a), adventure/exploration, independence, positive identity, and leadership (Henderson, Whitaker et al., 2007), and skill building (Carter, Lane, Pierson, & Glaeser, 2006; Garst & Bruce, 2003; Kiernan et al., 2004). Increases in outcomes related to self-esteem, independence, leadership, friendship skills, adventure/ exploration, and spirituality were maintained six months after camp (Thurber, Scanlin, Scheuler, & Henderson, 2007). Additional gains in leadership were found six months after camp (Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007).

To better document the developmental processes and outcomes of camps, the ACA embarked on a three-part study of outcomes associated with camp participation across the United States. The first study on outcomes of the camp experience documented benefits to campers' confidence, self-esteem, social skills, independence, leadership qualities, adventurousness, and spirituality (American Camp Association, 2005). The second study found that the greatest strength of camp was its support for caring relationships, but that opportunities for youth involvement (i.e. involvement in decision making during camp) had the most room for improvement (American Camp

Association, 2006b). In the third study, when camps implemented changes in camp structure, policies, and activities, 83% of the camps experienced improvements in campers' perceptions of opportunities for involvement and skill building (American Camp Association, 2006a). These studies were important because they were conducted on a national level, and because they were among the first to articulate the connections between what processes camps do on an organizational level and the developmental outcomes perceived by campers.

Still, other studies of camp have been inconclusive in their findings or have offered very little support to understanding how camps support development. For example, Henderson, Bialeschki, Scanlin et al (2007) found no statistically significant differences in developmental outcomes based on variations in camp components (e.g., staff training, length of enrollment, or camper to staff ratios). Henderson and her colleagues suggest that instruments may not have been sensitive to describing high quality camps, and that youth were already high in the outcomes measured for the study. Findings did demonstrate, however, that there was a trend toward positive growth in scores from pre- to post-test in adventure/exploration skills, making friends, positive identity, independence, leadership, and spirituality. Additionally, parents of campers reported statistically significant gains from pre- to post-camp in their children in the domains of adventure/ exploration, independence, making friends, positive identity, and peer relationships, and also reported gains in leadership six months after camp (Henderson, Whitaker, et al., 2007). However, these studies were limited in their ability to illuminate the contextual processes which might have influenced these outcomes.

A few studies have documented contextual elements found in camp that were related to youth development. Bialeschki, Henderson, Krenbiel, and Ewing (2003) interviewed camp counselors to understand what camp elements led to the achievement of camp goals such as the development of leadership, teamwork, skills and self esteem. They concluded that *camp culture* led to many of the stated outcomes. Specifically, they identified the following cultural components that influenced camp outcomes: (1) *opportunities*: offering new and unique experiences, overcoming fear, and accomplishments; (2) *camp structure*: length of involvement, focus on educational components, and outcome-focused programming; (3) *staff*: positive reinforcement, consistent behavior, and goal setting, and; (4) *campers*: determined to succeed, accountable for their actions, and peer support. Camps provide opportunities for youth to develop authentic positive relationships with peers and adults, as well opportunities for personal and social skill building (Henderson et al., 2007). These findings suggest for the value of further exploration into promising camp practices.

In another study related to camp context, Hill and Sibthorp (2006) found that campers' feelings of autonomy support (i.e., being given opportunities to make decisions) from camp staff were predictive of their perceptions of themselves as being more competent, autonomous, and related to others in their diabetes management. Henderson, Powell, and Scanlin (2005) observed that camps with clear and carefully supervised plans and curricula were those that reported positive change scores in outcome measures of positive identity, social skills, positive values, and thinking and physical skills. Other indicators of effective camp practices were frequent occasions for



group living, decision making, and activity participation. Opportunities for mentoring, problem-solving, and prosocial skill development were also found to be associated with positive academic outcomes over the course of a year (Hanes et al., 2005).

Another study examined features of camps and camp staff that affected personal and social outcomes for campers (Moorman, 1998). These two outcomes were enhanced in camps that charged less, were accredited, and had a general program focus (rather than offering coed sports). Personal outcomes were greatest in camps with directors who had bachelor's degrees (and/or graduate degrees in recreation and physical activity), for girls (but not boys), and for experienced campers. Henderson, Bialeschki, Scanlin, Thurber, Whitaker, and Marsh (2007) also suggested that contact and leadership from trained and experienced staff were instrumental in building supportive relationships that were essential elements of camp, as were program mission and structure, accountability, outcomes assessment, and the provision of skill building opportunities. Findings from these studies demonstrate how complex camps can be and the potential of these contexts to offer structured and unstructured opportunities to influence development.

Research on camps faces several limitations. Research during camp can be a difficult undertaking due to a lack of trained and available staff to support research efforts. Filling out surveys at camp is time-consuming and can be considered to be too much like school, which is the antithesis of the fast-paced and fun approaches of most camps. It is difficult to design studies to be experimental or quasi-experimental due to the difficulty in securing comparison groups and random samples during the summer, as well as ethical issues involved in withholding camp from willing participants. Study

participants usually are a self-selected sample. There are also high levels of study participant mortality when conducting follow-up surveys several months after camp; only a small number of studies include data from six months or less after camp participation. Many studies examine only one camp or use cross-sectional or pre-post test designs. This makes it difficult to examine lasting effects of camp.

The research that has been conducted on camps tends to suffer from additional issues. Small effect sizes are typically found, even with large national samples such as in the ACA studies. Evidence of ceiling effects plagues many studies; campers tend to come to camp with high scores on outcome measurement scales that leave little room to demonstrate improvement. Finally, camps in the ACA studies were accredited (i.e. met over 300 rigorous standards) which suggests homogeneity in program quality that makes it challenging to tease out program effects on outcomes.

It is difficult to control for other influences on youth's development, such as maturation effects. However, one study did find significant improvements in developmental outcomes after camp ended that were over and above youths' maturation effects (Thurber et al., 2007). Some empirically-based studies are emerging that examine specific developmental outcomes, such as in self-determination constructs (e.g., Ramsing & Sibthorp, 2008; Roark & Ellis, 2007). Additionally, ACA has recently developed and validated outcomes measurement scales for the constructs of friendship skills, independence, teamwork, family citizenship, perceived competence, interest in exploration, and responsibility (American Camp Association, 2008b). Camp research is becoming more empirically sound.

Professionals have usually viewed camp as a special place, yet until recently, relatively little has been done to delineate the specific outcomes associated with camp participation. Even fewer studies have addressed the processes that influence these outcomes at camp. These gaps in the research are even more pronounced when looking at camps that serve specific populations, such as youth with disabilities.

### **Camp for Youth with Chronic Illness and Disabilities**

Summer camp settings have long been used as an opportunity for youth with disabilities such as chronic illnesses to experience growth and learning through supported recreational programming (Goodwin & Staples, 2005; Klee, Greenleaf, & Watkins, 1997). Outcomes of camp for youth with disabilities tend to fall into several categories: (1) learning about oneself and positive identity, (2) learning physical and thinking skills, (3) learning about group living and social skills, (4) having fun, (5) gaining an appreciation of the natural environment, (6) developing positive values and spirituality (McAuliffe-Fogarty et al., 2007).

Studies of camps serving youth with chronic illnesses and disabilities have linked camp participation to developmental outcomes, such as decreased isolation (Goodwin & Staples, 2005; Michalski, Mishna, Worthington, & Cummings, 2003), increased social skills (Hanes et al., 2005; Meltzer & Rourke, 2005), medical adherence (McAuliffe-Fogarty et al., 2007), self-efficacy for health management (Ramsing & Sibthorp, 2006), and self-esteem (Wellisch, Crater, Wiley, Belin, & Weinstein, 2006). Most of these studies included youth with disabilities such as behavior disorders, or physical or cognitive impairments.

A few studies have been conducted with youth with chronic illness such as cancer (e.g. Meltzer & Rourke, 2005; Wellisch et al., 2006), epilepsy (or seizure disorders) (e.g. Meltzer & Johnson, 2004), and diabetes (e.g., Hill & Sibthorp, 2006; Hunter, Rosnov, Koontz, & Roberts, 2006; McAuliffe-Fogarty et al., 2007). However, these studies did not address how camp can be part of a broader developmental approach to building socio-emotional well-being, nor did they address the specific supports and opportunities found within the camp context that were related to positive youth development.

Participation in camps for youth with disabilities has also been linked to changes in self-esteem, social skills, and camp satisfaction (Michalski et al., 2003); competence for diabetes management (Hill & Sibthorp, 2006); perceptions of autonomy support (Ramsing & Sibthorp, 2008), and; social comparison, perceptions of self-competence, and social isolation (Meltzer & Rourke, 2005; Tiemens, Beveridge, & Nicholas, 2007). Michalski et al.,(2003) found that after participation in a camp program, youth reported less social isolation, modest improvements in self-esteem, and high levels of satisfaction with the camp. In addition, Goodwin and Staples (2005) discussed three themes of how campers with physical, sensory and behavioral disabilities found meaning through their camp experiences. These campers reported feelings of not being alone, independence, and having a chance to discover interesting experiences while at camp. Camp for these youth was a reprieve from the isolation found in their home environments, and a chance to explore identity.

While these developmental tasks are important for *all* youth, but some tasks may have unique significance for youth with disabilities who are faced with additional challenges in everyday life. For example, developing an intrinsic motivation to adhere to health practices is one area that can have serious repercussions for youth with chronic illness; those who do not become self-determined to take their medications face a lower quality of life, or even death. Youth with disabilities are influenced in their development by various systems in their lives, such as relationships with family, medical personnel, and peers. These multiple levels of influence can be sources of reinforcement and education concerning youths' conditions.

Camp can also affect youth's lives in ways that differ from medical clinics, tenuous peer relationships, and family stresses. Within the informal context of camp are opportunities for different approaches to teaching and learning health care practices than is typically found in more formal medical settings. One goal of many camps for youth with disabilities is to increase campers' medication adherence. In camp, techniques for medication adherence such as pill-taking, scheduling, reminding, and other tasks are taught in order to help to increase the quality of life for youth with chronic illness or disability (Grey, 1998; Guttman-Bauman, 1998).

Some studies have been conducted on the specific issue of medication adherence at camp, highlighting its importance for the well-being of youth with chronic illness, and how camp practices can reinforce messages that come from health care providers. For example, a sense of normality, motivation, energy, willpower, support from parents, and positive attitude toward illness were associated with medication adherence at a camp for

youth with diabetes (Kyngas, 2000). In another study, attitudes toward illness were shown to improve after participation in specialty camp programs (Austin & Huberty, 1993). A review of research on camps for youth with diabetes suggests that within the camp experience are opportunities for diabetes education, blood glucose control, regimen adherence, learning strategies for coping, and social support (McAuliffe-Fogarty et al., 2007). Such outcomes are thought to be made possible through the supportive relationships and opportunities for learning self-care found in the camp environment.

Some studies have linked camp participation with behavior changes beyond camp. In a nationwide mixed methods evaluation of 15 residential camps for over 2,000 youth with a range of disabilities, campers improved recreational and living skills, demonstrated high levels of enjoyment and participation in most camp activities, and were positively affected by their camp experiences (Brannan, Arick, & Fullerton, 1996). Personal development gains in communication, self-esteem, and particularly independence and self-reliance were found to carry over into home and community settings. However, this study was limited in its ability to ascribe these changes solely to camp, because it failed to link processes found within the camp experience to specific camp outcomes.

Some researchers have attempted to examine these processes. For example, Brannan, Arick, and Fullerton (2002) found that the five highest-ranked support types at camp were encouragement and motivational support, modeling, allowing extra time, arranging for peer assistance, and providing physical assistance. Hill and Sibthorp

(2006) found that autonomy support from counselors and staff at a diabetes camp was significantly and uniquely related to competence for diabetes management.

While gaps exist in knowledge about the outcomes of camp, and the processes that influence these outcomes, an even wider gap exists in examining camp-related outcomes and processes for different populations, such as youth with disabilities, and specifically those with chronic illness.

### **Youth with Chronic Illness**

Chronic illness in young people has been defined in several different ways, ranging from “medically fragile children” to “children with special health care needs” (Van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). The reported prevalence of youth with chronic illness ranges from as little as 0.22% to 44%, depending on the definitions utilized in different studies (Van der Lee et al., 2007). Commonly used is the “special health care needs” definition. Using this definition, Van Dyck, Kogan, McPherson, Weissman, and Newacheck (2004) found that in 2001, 12.8% (9.3 million) of non-institutionalized children (0-18 years old) in the United States “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care-related services of a type or amount beyond that required by children generally” (p. 884). In another study by Newacheck and Taylor (1992), approximately 30% of children and youth with chronic illness were found to have more than one chronic condition. The experience of chronic illness can be a tremendously disruptive force for youth, as well as for their friends and families. For example, having a child with special health care needs can result in financial burdens

from health care expenses, major caretaking demands, and loss of parental employment opportunities (Van Dyck et al., 2004).

Like all youth, youth with chronic illness face many psychosocial tasks necessary to their well-being and transitioning towards adulthood. Some specific issues faced by youth with chronic illness include feelings of isolation and restrictiveness, and assimilating the effects of the disease into various contexts of their lives. For example, youth with chronic illness often need to adjust their daily plans to take medications. Relationships with others are impacted as well, and include the tasks of developing supportive connections with others, negotiating responsibility for care, and disclosing their conditions to others. Additionally, youth with chronic illness must develop a “sense of coherence;” that is, the degree to which a person finds life comprehensible, manageable, and meaningful (Antonovsky, 1993). Doing so enhances a sense of psychological and overall well-being (Raty, Larsson, & Soderfeldt, 2003). Developing a sense of coherence is more influenced by age than by previous medical experiences (Aujoulat, Simonelli, & Deccache, 2006).

Research on youth with chronic illness tends to be problem-based; that is, it adheres to the traditional medical model focus on curing the symptoms or stopping problems from occurring, but there is a lack of attention to how the challenges of a chronic illness influence other areas of patients’ lives, such as their social, emotional, and mental well-being. For example, in a literature review, Sawyer, Drew, Yeo, and Britto (2007) found that much of the disease-specific research focuses on the effects of individual diseases and disabilities on adolescents and their families, as well as on



psychological adjustment/coping, co-morbid depression and anxiety, and health-risk behaviors. Other research tends to focus on outcomes related to familial impacts (e.g., Eiser & Berrenberg, 1995), transitioning to self-management of treatment (e.g., Freed Gary & Hudson Ericka, 2006; Stam et al., 2006), and risk behaviors that may exacerbate the illness (e.g., Miauton, Narring, & Michaud, 2003).

Fewer studies have examined the psychosocial development of youth with chronic illness. Psychosocial factors include stress, anxiety, fear, shame, frustration, and need for social support, which further interact with the seriousness, evolutionary characteristics, and potential incapacity of the illness. Studies on youth with chronic illness tend to be framed in terms of recommendations for health care providers' use of best practices in educating and counseling youth as they address the medical and psychosocial aspects of their illnesses (Aujoulat et al., 2006).

Some efforts have been made to connect the psychosocial experiences of youth with chronic illness to the experiences of those without such conditions. As Eiser and Berrenberg (1995) noted, "Children with chronic disease are normal children facing a crisis; they are not deviant or maladjusted" (pp. 110-111). One study suggested that the goal of programs for youth with chronic illness should be to promote positive youth development, including competence, confidence, connectedness, character, and caring, as well as independence, opportunities for socialization with peers, and use of coping resources and strategies (Aujoulat et al., 2006). Use of coping resources and strategies is consistent with a resiliency approach, which aims to identify and characterize those

factors that lead to positive and negative outcomes for individuals when they are faced with extreme stress (Small & Memmo, 2004).

In order to address these goals, Sawyer et al (2007) recommended that researchers take the following into consideration when working with youth with chronic illness: the wide range of variation of outcomes in adolescence; developmental outcomes of care from earlier in childhood that manifest in adolescence, care found outside of the traditional health-care system such as schools and family planning centers, and improved measurement instruments for determining quality of life. Additionally, the authors suggested that a major goal for youth with chronic illness is optimal self-management. This includes development of problem-solving ability, technical skills, and self-efficacy for behavioral changes that are necessary to navigate the transition from parental to youth responsibility for self-care. Such goals echo those found in the positive youth development literature.

One unique issue related to youth with chronic illness as they transition toward adulthood is their health-related quality of life (HRQOL). In a study that compared youth with epilepsy to a random sample of the general population, researchers found that the epilepsy group had lower competence (less active, lower social competence and school achievement) than the general population. Additionally, for both groups, girls and older youth had lower HRQOL than boys and younger children respectively, (Raty et al., 2003).

Stigma can be an important factor impacting the lives of youth with chronic illness. Stigma occurs when differences are highlighted and associated with negative

attributes, and can result in separation of “us” from “them” as well as status loss and discrimination (Link & Phelan, 2001). These interrelated components affect multiple domains of life, and thus have major bearing on the quality of life. For certain illnesses such as HIV/AIDS or mental illness, health status is not always readily apparent to others. Youth with these conditions may form perceptions about how others will view them, and fear being negatively labeled, devalued, and discriminated against based on their illness. This is a similar concern for people with mental disorders, which is another “hidden” condition. Such concerns and fears have been termed “modified labeling theory by Link, Cullen, Struening, Shrout, and Dohrenwend (1989). This theory suggests that concerns about stigma may result in people with mental disorders feeling threatened by interacting with others. Coping strategies to avoid threats include keeping treatment a secret, educating others about the illness, or withdrawing from potentially rejecting social contacts. However, the authors suggest that these strategies can result in negative consequences regarding support networks, jobs, and self-esteem.

Successful coping with the effects of chronic illness is predicated on the availability of contexts that support development. One study on adolescents with cancer found that their HRQOL was significantly better, and their anxiety and depression was significantly lower than adolescents without cancer a year and a half after diagnosis, while the reverse was true immediately after diagnosis (Jorngarden, Mattsson, & von Essen, 2007). These findings were attributed to successful adaptation to trauma in the adolescents with cancer. This was based on posttraumatic growth and response shift caused by changing internal standards, values, and concepts related to quality of life,

such as finding satisfaction and meaning in the ordinary, and with less. Austin and Huberty (1993) found a strong relationship between children's attitudes toward their chronic condition and their self-concept, and suggested that long-term chronic illness in childhood becomes a part of one's identity. Unfortunately, studies on HRQOL are often plagued with methodological concerns, for example, the ability of children and parents to make dependable assessments because life with chronic illness is the only life they know (Sawyer et al., 2007).

One method of coping with chronic illness is to engage in risky behaviors in order to feel a sense of control over life. Studies suggest that youth with chronic illness are actually more likely to engage in experimental behaviors (Miauton et al., 2003). This places youth with chronic illness at a "double disadvantage;" that is, more frequent and intense risky behaviors compounded with more adverse health outcomes from these behaviors (Sawyer et al., 2007). Such behaviors are not always inherently bad, as Miauton et al argue; active sensation seeking is part of the development of personality, independence, autonomy, and maturity that all youth experience as they grow. Yet, with such experimental behaviors comes a need for protective factors and support from close friends, family, and health care providers to cushion against the potential negative consequences of experimental behaviors. Protective factors are needed due to the increased propensity that youth with chronic illness have toward: higher anxiety and violent or sexual victimization; negative body image; lower perceived popularity, self-confidence, self-esteem and self-worth, and distance from peer culture (Miauton et al., 2003). Furthermore, one study showed that youth with a history of pediatric disease

achieved significantly fewer developmental milestones (i.e. autonomy, psychosexual, and social development), or at an older age than their peers (Stam et al., 2006).

Several emotional and social factors may serve to dampen negative experiences for youth with chronic illness. For example, youth found support, understanding, encouragement, acceptance, and education on their disease and treatment through relationships with peers at a residential camp for children with cancer, whereas they typically did not experience such support from their healthy friends (Bluebond-Langner et al., 1991). Group and individual activities designed to optimally challenge youth while providing fun and relaxation are the hallmark of youth development programs. Trained staff of such programs can serve as important supports for youth through their mentorship, connection to resources, and facilitation of positive social relationships. Self-determination (rather than being extrinsically motivated by others) can be nurtured in youth via opportunities to make choices, engage in relationships, and gain competence (Ackerman, 2006; Robinson & Lieberman, 2004; Ryan & Deci, 2000), and provide youth with internal coping resources.

Recreation and leisure activities can be therapeutic because they contribute to social, emotional, and cognitive health by providing opportunities for prevention and transcendence of negative life events, and for coping with challenges (Caldwell, 2005). Leisure can serve as a buffer to the effects of difficult proximal life circumstances, and can sustain coping efforts through a sense of competence and continuity of self, including connection or continuity to one's past, and symbolically to one's values, beliefs, sense of self, and personal histories (Hutchinson et al., 2003). These

opportunities are afforded in leisure via freedom to engage in the activities, and freedom from constraints that inhibit full engagement. While structured leisure activities are certainly important for all youth, they may serve an additional role in the lives of youth with chronic illness by providing accessible and supportive opportunities to engage outside of family and school contexts. This facilitated engagement can lead to positive developmental outcomes that enable the successful transition into adulthood.

### **Youth with HIV and AIDS**

Developmental issues such as those described above are congruent with the experiences of youth with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). However, there are qualitative differences in their experiences due to the nature of this disease. These differences mainly include medication adherence, disclosure, and family considerations. While these issues may be present for people with other disabilities, they are especially salient for people with HIV/AIDS because of the particular stigma associated with HIV and AIDS due to its perceived connections with deviant behaviors.

The Centers for Disease Control and Prevention (CDC) reported that 9,112 children under age 13, and 6,354 youth ages 13-19 were diagnosed with AIDS in 2005 (CDC, 2007). Child Trends reported that twenty percent of children and youth with HIV develop AIDS and pass away within four years, and that AIDS is related to significant health problems, such as learning how to walk, having seizures, experiencing difficulties in school, and being sick more often and more severely than non-infected youth (Child Trends Databank, 2007).

Since 1994, vertical HIV transmissions (i.e. virus is passed from mother to fetus) have decreased to almost nothing due to advancements in antiretroviral treatments during pregnancy and labor (Rogers, 2006). Additionally, in the 1980s, life expectancy for children with HIV and AIDS was short; with the advent of highly active antiretroviral treatments (HAART), children born with HIV are surviving well into adulthood (Ledlie, 2000). This has implications for managing developmental transitions, such as addressing issues related to intimacy, self-care, and family transitions (due to parents also affected by AIDS). The nature of HIV and AIDS for both young people and adults remains poorly understood, and this lack of understanding complicates attempts at identifying promising practices for treatment and interventions.

Some information and understanding has been developed, however. It is important to discuss issues related to physical and cognitive development, medication adherence, disclosure, and familial influences on youth with HIV/AIDS. These issues are highly intertwined.

HIV impacts physical health in several ways. It causes neurocognitive impairments that affect behavior and learning, such as lower attention and language ability, and encephalopathy, which in turn affects brain growth, motor skills, and delay in developmental milestones, (Brown, Lourie, & Pao, 2000). Forsyth (2003) also described medical issues facing youth with HIV. Youth with HIV are vulnerable to opportunistic infections such as pneumonia and meningitis, and to lung disease and lymphomas. Forty to ninety percent of youth have some degree of central nervous system disease. Physical growth is typically stunted, causing weakness and flaccidity,

and youth also have abnormalities in motor and cognitive development. Additionally, youth with HIV/AIDS typically have other health issues related to birth defects (such as fetal alcohol syndrome), medication side effects, and drug interactions (Forsyth, 2003).

In the mid-1990s with a greater understanding of HIV and AIDS came highly active antiretroviral therapy (HAART), which improved mortality and morbidity (Forsyth, 2003). However, these regimens are difficult to adhere to, due to nausea-inducing pills or injections needing to be taken frequently during the day under specific circumstances. It is crucial to take medication as prescribed, for viral resistance and loads increase, and immune status decreases when the treatment regimen is not adhered to (Brown et al., 2000). It has been well-documented that adherence to medication regimens is frequently suboptimal for children and adolescents, and that patterns reflect those of the adult population (Naar-King et al., 2006; Steele, Nelson, & Cole, 2007). For example, 26-59% of youth participants missed doses in the week preceding several of the data collection periods in studies on adherence. However, disparities were found in the metrics, methodologies, and definitions of “adherence” in the reviewed studies (Steele & Grauer, 2003), making accurate assessments of adherence difficult.

There are several reasons for non-adherence. In a literature review, Steele and Grauer (2003) found that common correlates of adherence for youth with HIV/AIDS include medication and dosing characteristics, health beliefs, perceived social supports, depressive symptoms, and environmental conditions (i.e. living situations), caregiver perceptions of medication efficacy and dosing self-efficacy, parental psychological well-being, and youth characteristics (i.e. age). Using a social ecological model, Naar-King et



al (2006) found that caregiver drug and alcohol use and positive status were associated with non-adherence and increased viral load in their children. Also, negatively viewing outcomes of medication adherence and feeling less healthy and energetic were related to lower adherence. Interestingly, general family functioning was not directly predictive of adherence and viral load, perhaps because of low reliability of the measurement instruments due to their inability to accurately measure non-traditional family structures.

Other studies have identified areas of familial involvement that impact adherence, such as parent-child communication, levels and types of disclosure, and stressors (Steele et al., 2007). Family-related medical issues include self-management of medication such as adhering to strict schedules, making treatment decisions, planning for transition of care, and interactions with medical personnel (difficult for all adolescents, but especially for those with HIV/AIDS who may be hesitant to share personal information with strangers). In a review of literature from a socioecological framework, Steele, Nelson, and Cole (2007) discussed several psychosocial issues affecting young people with HIV/AIDS such as behavior, emotions, gender, age, social support availability, coping, and quality of life differences. Family issues include bereavement, changes in primary caregivers (and their willingness and ability to provide care to youth), and considerations due to familial poverty, violence, and drug use.

These issues are complicated by social ecologies of youth with HIV/AIDS that are typified by poverty, difficulty in accessing resources, a lack of social support, chaotic family issues (such as parental drug use, illness, and death), and cultural beliefs regarding the disease (Naar-King et al., 2006; Steele et al., 2007). Personal issues within

the social ecology include fear related to the loss of parents and caregivers, loss of relationships once status is disclosed, pain from treatments, and resistance to difficult treatment regimens. Individual social factors related to HIV/AIDS include disclosure (both to the youth with HIV and to their friends and family) and stigma.

Disclosure, as a broad term, thus becomes an overarching issue in the lives of youth with HIV/AIDS. Wiener and Lyon (2006) discussed several issues related to the concept of disclosure. First, youth must learn that they have HIV, which can be upsetting if done inappropriately; parents and caregivers often do not tell youth that they have the illness due to shame or desire to protect their children from the potentially negative effects of stigma. Second, youth must decide which family members and friends (if any) to tell. Youth must also make decisions on how to disclose status to others with some level of involvement in their health, such as school nurses or sports team coaches. Finally, youth need to learn how to disclose status to potential romantic partners. Decisions of whether, when, and to whom to disclose their illness is a unique aspect of HIV (Steele et al., 2007). This uniqueness arises from the particular stigma associated with HIV/AIDS, and this stigma is often due to perceptions about the nature of the illness and especially its contagion. However, overcoming effects of stigma is critical for young people to exercise their right to access to comprehensive health care (de Carvalho Mesquita Ayres et al., 2006).

One study on a non-clinical, psychosocial intervention for youth with HIV/AIDS was identified during this literature review. This qualitative study reported on the importance of family empowerment (i.e. autonomy, self-esteem, and self-efficacy) in

restoring self-efficacy and self-esteem and developing positive coping and decision-making processes, and described differences in settings for psychosocial interventions between outpatient clinic and a therapeutic family camp (Kmita et al., 2002). The authors concluded that involving different settings in psychosocial interventions seems to be optimal, especially for highly vulnerable families. It was more difficult to motivate families to attend meetings in a medical context, but easier to interact with families in the camp setting. For example, camp group activities (parent and youth support groups, singing, walking) seemed the most effective avenue for both children and caregivers to express themselves and their feelings, and seemed to have lasting influence on participants' decisions to disclose HIV status to others. However, this appears to be the only camp-related study of youth with HIV/AIDS. One possible reason for the dearth of information about youth with HIV/AIDS at camp is the difficulty in gaining research access to this population due to concerns about the critical need for confidentiality of camp participants.

### **Summary**

This literature review revealed gaps in the state of knowledge about connections between processes and outcomes in youth development settings, summer camp, and for programs serving youth with HIV/AIDS. The few published studies on processes and outcomes associated with camp indicate a larger need to examine the “black box” between participation in a program and participant outcomes. The few studies on psychosocial contexts for youth with HIV/AIDS further highlight a need for more research with various groups of youth. These conclusions support the need for the

current study and the study's ability to contribute to the body of knowledge on the processes and outcomes associated with camp participation for youth with the chronic illness of HIV/AIDS, and to inform the theoretical foundations of the field of positive youth development.

This chapter reviewed the literature on positive youth development, supports and opportunities, camp, camp for youth with disabilities, youth with chronic illness, and youth with HIV/AIDS. The literature review highlighted the different approaches to youth development coming from the OST field as compared to the medical field. Both fields support the youth development paradigm, but the processes by which they propose development occurs are qualitatively different. Additionally, the literature review suggested that the logical connections between camp program components and outcomes for campers need clarifying, and this clarification needs to be able to be applied to specific groups of youth, such as those with HIV/AIDS. By doing so, assurance can be provided that the positive youth development framework is applicable to *all* youth, not just “youth in general.”

### CHAPTER III

#### RESEARCH METHODS

The purpose of this study was to understand the developmental outcomes related to participation in camp, and the processes within camp associated with these outcomes. An interpretive case study framework was used to investigate the research questions (Yin, 2003). The case was a six-day camp for youth with HIV/AIDS ages 6-15 called Camp Hope. Three data collection times comprised the case. First, focus groups, interviews, and observations were conducted at a program evaluation in 2007 at Camp Hope. Second, interviews and observations were conducted at a Camp Hope-related program for 20-30 youth with HIV/AIDS ages 15-19 called UniversalTeens in early summer 2008. Third, interviews and observations were conducted at Camp Hope in late summer 2008.

Data were gathered through interviews with a total of 17 campers, one caregiver, and 15 staff, six focus groups with a total of 19 campers at Camp Hope, unstructured participant observations conducted during Camp Hope, and artifact review. Data analysis used a grounded theory approach employing the constant comparison method (Strauss & Corbin, 1998). Validity and reliability were ensured through multiple sources of evidence (i.e. triangulation of data sources, investigators, theories, and methods; Yin, 2003), member checks, and acknowledgement of biases and limitations. Data analysis resulted in description, conceptual ordering, and theorizing (Strauss & Corbin, 1998).

I begin by explaining the rationale for using an interpretive case study framework (employing interviews and observations) to investigate the research questions, and define the unit of analysis. Next, I explain the data collection procedures, descriptions of the data analysis, and explanations of efforts to ensure trustworthiness and validity. I conclude with information regarding my identity as a researcher, and limitations of the study.

### **Research Design**

Qualitative research is defined by Creswell (2003) as an approach to inquiry in which the inquirer constructs knowledge to make claims, using strategies such as case studies or phenomenology. Open-ended, emerging data is collected from participants with the intent of creating themes from the data to develop theory or describe social phenomena. Qualitative research is a fundamentally holistic and interpretive approach using multi-faceted, iterative, and simultaneous complex reasoning, as the researcher aims to be systematically reflexive. Qualitative methods are multiple, interactive, and humanistic, and take place in the natural setting of the participants (Creswell, 2003, pp. 181-183).

#### *Rationale for Interpretive Case Study*

Case study methodology is used when researchers ask “how” or “why” questions about complex social phenomena. As Yin (2003, p. 13) suggests, a case study is an empirical inquiry that

investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident;

cope with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result, benefits from the prior development of theoretical propositions to guide data collection and analysis.

The use of case study methodology was appropriate for this study because I explored multiple bounded systems over time through the use of interviews and observations, and the outcomes of this research are a case description and case-based themes (Creswell, Hanson, Plano Clark, & Morales, 2007). The case of interest in this study was a camp for youth with HIV/AIDS. The aim was to develop an in-depth understanding of how the camp experience provided supports and opportunities for positive youth development to campers through the exploration of processes and outcomes at this camp.

Given these goals, this study is an interpretive case study, and is not a descriptive or evaluative case study (Yin, 2003). Focusing on interpreting outcomes for campers guided by the tenets of positive youth development is important in refining our understanding of how participation in camp leads to specific outcomes.

#### *Rationale for Use of Interviews*

The successful use of in-depth interviews as the primary data collection method required several conditions, including time, multiple interviews, attention to communication and emotions, flexibility, and guidance from the ongoing interaction with the participants (Ellis, Kiesinger, & Tillmann-Healy, 1997). Marshall and Rossman

(2006) suggest that the interviewing method has strengths and challenges. Interviews yield much data quickly about participants' perceptions, and there is opportunity for probing questions to clarify and expand on participants' answers, especially those related to complex phenomena. Interviews also allow for flexibility in the exploration and development of hypotheses by providing context information and triangulation that provide a deeper understanding of the phenomenon of camp as a setting where youth can have supports and opportunities for development.

Challenges associated with interviewing include the basic need for personal interaction and cooperation. Additionally, participants may be uncomfortable sharing information, such as negative experiences during or after camp, or highly personal medical information. Participants may feel compelled to give socially desirable answers. Still, the use of interviews is a useful method for gaining information about phenomena.

#### *Rationale for Use of Observations*

In addition to interviews, this case study also relied on observations of people, events, and objects to ensure multiple information sources. There were two parts to the observational portion of this study: unstructured observations and artifact review.

The purpose of the observations was to provide a description of the setting, the activities and people within the setting, and what meanings were ascribed to them from the perspectives of those observed (Patton, 2002). Patton explains that other purposes of observations are that the researcher can provide a more open and discovery-oriented approach to conceptualizing the setting that may be missed by those who are immersed in it. Additionally, observations provide an opportunity to learn things that people may



not talk about in interviews, whether due to unwillingness to share because of embarrassment or ascription of unimportance to a behavior, for example.

Yin (2003) suggests that there are strengths and weaknesses to gathering observational evidence. Strengths of direct and participant observations include the opportunity for observing reality and context, and gaining insight into behavior and motives. However, weaknesses of such observations include the process being time-consuming, costly, and the existence of limitations due to selectivity, reflexivity, and possible manipulations of events. In addition, Patton (2002) also suggests that limitations of observations is that the researcher's presence may affect the study location in unknown ways, that people may behave differently if they feel observed, and that selective perception may miss important data. Finally, observations are limited to what the researcher can actually observe; people's internal feelings and events outside of the researcher's awareness cannot be observed.

Regarding artifact review, Yin (2003) suggests that strengths of observing objects such as documentation, records, and artifacts include their being stable over time, unobtrusive, exact/ precise, broad over many events and settings, and insightful into cultural features and technical operations. Weaknesses of observing such objects include difficulty in accessing and retrieving items, incomplete or inaccurate items, and research bias in selecting and reporting on items.

Even with the limitations inherent in these methods, use of interviews and observations yielded much information that was appropriate for the aim of the study.

Seeking to answer “how” and “why” questions, interviews and observations were the most relevant methods to understand the developmental role of camp in campers’ lives.

### **Unit of Analysis**

The unit of analysis was a summer camp program (Camp Hope) operated by AIDS Foundation Houston (AFH) and conducted at the Camp For All (CFA) facility during the summers of 2007 and 2008. Additionally, interviews with former Camp Hope participants were conducted at UniversalTeens (a Camp Hope-related program) in early summer 2008. This study is delimited to these three primary data collection locations and times. Next I describe the three data collection locations and times, how they were selected for the study, and my role at each one.

#### *Camp For All*

Camp For All is a barrier-free residential camp facility located in Burton, Texas. The camp features indoor and outdoor experiential activities for youth with special needs. Camp For All serves agencies that offer summer opportunities for youth by providing recreation, educational, and therapeutic programs designed to enhance self-esteem, self-awareness, and independence. There is a year-round camp staff that provides programs for youth and serves several agency-based camps that take place at CFA over an agreed-on week during the summer. Partner camps provide their own staff members who work directly with youth and assist with transportation, medical needs, and general care for campers while they are at camp.

In 2007, CFA agreed to participate in a longitudinal study conducted by Texas A&M University about the outcomes of camp for four of their partner camps. I was the

project director for this study at CFA, and was thus introduced to Camp Hope (operated by AIDS Foundation Houston, the partner agency). While the present study was distinct from the longitudinal program evaluation because it was a case study of only one partner camp during one summer, it was also related to the evaluation because this case study was conducted with one of the four partner camps that also participated in the longitudinal study.

### *UniversalTeens*

AIDS Foundation Houston also operated a camp-related program (UniversalTeens) that was held at the University of Houston for a week in early June for youth ages 15-19 who aged out of Camp Hope. The camp director was responsible for both programs. In 2008, fifteen of the 19 participants of UniversalTeens attended Camp Hope in the past. The purpose of the program was to build concrete life skills as these youth transition into adulthood through educational workshops and activities.

While discussing how I would access the UniversalTeens participants for interviews, the camp director invited me to volunteer as a mentor at UniversalTeens, which would provide easy access to potential interview participants, and more opportunity for understanding the role of camp in these youth's lives. Additionally, I gained insights into the life experiences of UniversalTeens participants through informal interactions with them during the program. For example, while I was driving a group of participants, I engaged in a long conversation with a former Camp Hope camper about his feelings about his friend from camp who had recently passed away.

### *Camp Hope*

This was the unifying experience for all study participants. Prior to initiating the study, meetings were held to identify potential camps associated with CFA and their ability and willingness to engage in a case study. Camp Hope was chosen as the case study because it focused on campers with chronic illness, utilized more mature and professional volunteer camp staff than other CFA partner agencies, and had a camp director who expressed enthusiasm and support for outcomes studies. The camp director had over 10 years experience working with CFA and felt comfortable about including research into the camp programming. He also had a desire to better understand the outcomes of participation in camp for the campers, as demonstrated during his participation in the program evaluation conducted at CFA with Camp Hope in 2007. Additionally, as discussed in the previous chapter, research on psychosocial programs for youth with HIV/AIDS is scant.

My role at Camp Hope was as one of three counselors in a cabin of twelve 13-15 year old girls. Prior to the camp session, I spoke with the Lead Counselor about my desire to conduct research activities during camp, and how that would occasionally take me away from cabin responsibilities. Soon before the campers arrived, I worked with the other counselors to identify and schedule good times for me to be away from the assigned cabin group, and times when my help would be needed with the group. In the beginning, it seemed that we had a satisfactory arrangement, but by the end of camp, I realized that the other two counselors seemed stressed about the arrangement. Their stress was likely related to having more responsibility than anticipated placed upon them

when I left the group to conduct interviews and observations. Even though I consistently told them when I would be leaving and returning, and they seemed fine with it, my research responsibilities might have caused a rift in the leadership of the cabin.

Additionally, I did not bond with the campers as well as I would have liked due to being away from the group at least twice a day for an hour or two at a time. Looking back, it would have been helpful to have had a fourth counselor in the cabin to spread out some of the supervisory burden.

Still, I was able to function as a part-time counselor and connect with a few of the girls in the cabin. Counselor responsibilities included making sure the campers got to their activities on time, telling them what time it was and how much longer they had to get ready to go to the next activity, reminding them to drink water and gather their belongings, participating in activities with them, and informally talking with them.

### **Data Collection Procedures**

Data were collected during three timeframes: summer 2007, and two programs held separately during summer 2008: UniversalTeens and Camp Hope. Summer 2007 data consisted of information from focus groups with campers, interviews with camp staff, and unstructured observations at CFA. Summer 2008 data consisted of information from interviews with campers, camp staff, and one caregiver from UniversalTeens (held at the University of Houston) and Camp Hope (held at CFA). Table 1 summarizes the data collected in this study.

Table 1. *Summary of Study Data.*

<b>Data Collection Site</b>	<b>Focus Groups</b>	<b>Individual interviews with campers</b>	<b>Individual interviews with staff</b>	<b>Interviews with caregivers</b>	<b>Observations</b>
July, 2007 Camp Hope (CFA)	6 focus groups with 19 youth ages 7-16	None	1 with camp director; 1 with social worker; 1 with doctor; 4 with counselors	None	Informal, 10-20 minutes in dining hall and activity areas (3 people at 2 activities each)
June, 2008 UniversalTeens (University of Houston)	None	8 interviews with 9 campers (1 interview was with 2 campers)	Unstructured discussions with camp director and co-mentor	1	Participant observations in a mentor role, artifact review
July, 2008 Camp Hope (CFA)	None	8 interviews	1 formal interview with counselor; 4 informal interviews with counselors; 1 informal interview with doctor; 1 informal interview with social worker; 1 formal and 1 informal interview with camp director	None (unsuccessful)	Participant observations in a counselor role, artifact review, unstructured observations
<b>Total:</b>	19 campers	17 campers	15 staff	1 caregiver	14 days as participant observer

### *2007 Data from CFA Program Evaluation*

During summer 2007, a program evaluation was conducted by Texas A&M University at CFA of four camps for youth with HIV/AIDS, seizure disorders, muscular dystrophy, or cancer. These primary stakeholder camps of CFA were selected for participation due to their in-depth knowledge and experience operating a partner camp at

CFA, and for their different perspectives on possible youth development outcomes associated with camp. The inclusion of these different perspectives was designed to triangulate the data sources in the attempt to better understand the outcomes of participation in camp for various types of campers. Interviews were held with CFA and the staff of the partner agencies, and focus groups were conducted with campers to collect baseline data about outcomes associated with camp participation. The intent of the evaluation was to articulate a program logic model, and develop and implement outcome measurement strategies for a subsequent three-year evaluation of the CFA program. The long-term evaluation strategy was designed to employ a comprehensive assessment of processes and outcomes.

For Camp Hope participants the 2007 evaluation included: six focus groups with a total of 19 campers ages 7-17, six interviews with staff, one interview with the camp director, and unstructured observations. A team of three graduate students conducted the interviews, focus groups, and observations. Probes for focus groups and interviews were frequently used to gain deeper understanding of participants' responses. The following explains why and how data were gathered from these stakeholder groups affiliated with CFA.

### **Interviews with Camp Director and Staff**

In-depth interviews were held with the camp director and camp staff (see Appendices A and B respectively for the interview guides) with the purpose of understanding what they perceived to be the outcomes of camp for their campers. Interviews were conducted with the camp director to gain an overall understanding of

camp, such as information about the partner agency's goals for campers, past experiences operating camp, and future directions of camp. Camp director interviews took 20-45 minutes. Camp staff interviews were conducted to elicit information about their perceptions of camper outcomes related to camper participation in camp, and took 10-20 minutes each.

Camp staff who had worked at camp for a minimum of two summers were selected for interviews and asked to discuss what changes were observed in campers after attending camp. Camp staff interview participants mostly included counselors who lived and worked with campers throughout the week. Additionally, medical and psychosocial staff members were interviewed to gain another perspective of how campers experienced camp. Medical staff consisted of doctors, nurses, and other health care providers who had knowledge of typical medical issues faced by campers, and resources at camp designed to meet their medical needs. Psychosocial staff consisted of social workers and case managers of campers who had knowledge of campers' home environments and common psychosocial issues that arose for campers during camp. Interviews with all staff occurred during staff training the day before campers arrived at camp. Interview questions with all staff centered on: how they came to be in their position, daily and weekly schedules, out-of-camp contact with campers, campers' perceived motivations to attend camp, changes observed in campers due to camp, and campers' activity preferences. The goal of the staff interviews was to understand perceived outcomes of camp for campers through the eyes of adults who were engaged in close relationships with campers at camp, sometimes over several summers.



### **Camper Focus Groups**

Focus groups were conducted with campers to elicit information about the outcomes of their camp participation and their lived experiences at camp (Appendix C). Focus groups were conducted with groups of 3-5 campers after lunch on the fourth day of camp, and took 10-15 minutes each. Camper groups were formed based on their age and level of past experience at camp (i.e., veterans or first-timers). The demographic profile of the focus group participants reflected the camp's demographic profile; i.e. nearly all were African American, a few were Hispanic, and couple were White. Focus group questions centered on activity preferences, camper-staff interactions, what new things were done during camp, what camp meant to the participants, what they learned about themselves at camp, if there were any changes in themselves, and if they planned to do anything differently in their lives outside of camp. The goal of camper focus groups was to understand the experiences of campers during camp.

### **Observations at Camp**

In addition to the interviews, unstructured observations were conducted before and after the camper focus groups. The interviewers spent 10-20 minutes at different activity sites, such as canoeing, fishing, drumming, and cooking. Additionally, the interviewers observed camper and staff interactions in the dining hall during lunch and as campers and staff entered and left the dining hall. The goal of the observations was to explore interactions between campers and between staff and campers in the natural setting of camp. Activities were selected to facilitate gathering information during a variety of camp experiences (i.e. scavenger hunt, swimming, and canoeing). Interviewers

were instructed to simply observe what was happening at each of the sites. Later, the interviewers met as a group and informally discussed their observations of the activities and their interviews. A list of common themes and comparisons between camps was created as a result of these discussions.

To conclude, existing data from interviews with campers and camp staff in summer 2007 were used to supplement data gathered in the current study, and were organized and analyzed according to the current study's research questions.

#### *2008 Data from UniversalTeens and Camp Hope*

Data collection in summer 2007 focused on understanding the outcomes of camp participation for campers, and used a triangulation of data sources and methods to yield information specific to the study's purpose. However, as preliminary analyses occurred, what became less clear was an understanding of the supports and opportunities for positive youth development that existed within the camp experience. This became the impetus for the current study. Thus, the purpose of the current study was to better understand the developmental context for youth with chronic illness at camp. Findings from the current study resulted in a refinement of our understanding of the outcomes that are associated with participation in camp, and the processes at camp that facilitate youth development which were based on data collected during 2007.

Data for this study were collected at two Camp Hope-related summer programs operated by AIDS Foundation Houston: UniversalTeens (early June 2008) and Camp Hope (late July 2008). The purpose of UniversalTeens was to provide youth ages 15-19 with HIV/AIDS (those who have aged out of Camp Hope) a forum to learn life skills for

transitioning into adulthood. This purpose was enacted through exposure to various supports and opportunities for development such as inspiring people, information on college, adult health care procedures, and more. The purpose of Camp Hope was for youth ages 7-15 to experience a fun week at camp while learning about “a life outside of the world they live in,” (camp director, personal communication, July 14, 2007). This purpose was enacted through camper engagement in recreational activities at camp such as a ropes course, swimming, and dances. Additionally, an educational program called Teen Talk provided a forum for campers 12 and older to learn about HIV.

The camp director agreed in April 2008 to facilitate interviews with campers, to provide contact information for parents/caregivers for interviews, and to allow me to be an observer at both programs. Next, I discuss the procedure for the 2008 data collection.

#### *Procedure*

While any camp could have been chosen for this study, Camp Hope was selected due to my preexisting relationship with CFA as a project director of the longitudinal outcomes study, CFA’s geographical proximity to Texas A&M University, and the willingness of both the Camp Hope director and the CFA president and chief executive officer to participate in the study. The Texas A&M University Institutional Review Board approved the study. Prior to camp, all campers given consent forms for their caregivers to sign in order for campers to participate in the study (Appendix D). Caregivers of campers provided their consent prior to camp for their children’s participation in the study. Camp staff signed consent forms for themselves at camp. Assent for study participation was given by all study participants prior to all interviews.

See Appendix E for the assent procedure and interview questions. The interviews were digitally recorded, and later transcribed verbatim. Observations occurred before and during camp, and artifacts were collected before, during, and after camp.

### **Interviews**

In-depth interview questions are located in Appendix E. These questions were reviewed by my dissertation committee and advisor and then shared with AFH and CFA for review and approval. An original procedural aim of this study was to pilot test the interview questions at a weekend camp program at CFA. However, due to changes in goals and staff for the program, this access was unavailable. Instead, questions were refined during interviews at UniversalTeens, and additional questions were added to address issues of disclosure for Camp Hope participants. Interviews with campers lasted 20-40 minutes, formal and informal interviews with camp staff lasted 10-40 minutes, and interviews with the camp director lasted 30-60 minutes. The interview with the caregiver was conducted via email communication.

Another common data collection method is the use of focus groups; however this method was not used in 2008 due to the study's intent to gather more in-depth information than that elicited during focus groups in summer 2007. While these focus group data were useful in identifying a range of outcomes, they were limited in their ability to link those outcomes to processes within camp and to provide a sense of the role that camp plays in youth's lives. These limitations occurred because the 2007 focus groups were short (10-15 minutes) due to campers impatiently wanting to return to their fun activities, and rapport between the interviewer and participants was difficult to

achieve given the very brief introductory time period prior to the focus group. Camp activities were perceived by campers to be more fun than focus groups. Additionally, focus group participants would frequently repeat the answers that others gave which suggested “group think,” even if the interviewers asked probing questions. Focus group questions resulted in somewhat superficial answers, especially for younger participants. In the 2008 study, it was expected that focus groups could similarly reflect ‘group think’ biases. Another limitation was that there could have been some instances that occurred before, during, or after camp that campers or staff would not feel comfortable talking about in a group setting. Finally, the purpose of the study was to understand developmental outcomes related to camp participation, and it would be difficult for the interviewer to provide individual attention in a focus group. These lessons learned during summer 2007 were applied to the current study.

### *Interview Participants*

The 2008 study focused on campers ages 13 and older who attended Camp Hope for at least one previous summer, caregivers of campers, and camp staff. Each of these individuals had unique insights that provided converging and diverging perspectives of outcomes, and the processes that lead to these outcomes. Examination of the similarities and differences between study participants’ reports, given their differing standpoints, added validity to the findings.

### **Campers**

Campers were included in this study because their lived experiences at camp were of primary importance in understanding their perceived outcomes due to camp

participation, perceptions of supports and opportunities at camp for development and growth, and the role of camp in their overall developmental context.

I conducted in-depth interviews with a total of 17 campers ages 13-19 who attended camp for at least one previous summer. These interviews were about their experiences at Camp Hope, and were conducted at both UniversalTeens and Camp Hope. Campers were selected for interviews in consultation with the camp director to ensure a variety of attitudes toward camp and levels of camp involvement. Nine interview participants were African American, three were Hispanic, three were of mixed race, and two were White. Seven participants lived in the Houston area, six lived in Florida, and four lived outside of the Houston area in Texas. Two participants were 14 years of age, four were 15, five were 16, four were 17, and two were 18.

The purpose of the interviews was to explore campers' memorable camp experiences, the meaning of camp in their lives, relationships with other campers and counselors, comparison of camp to other life experiences, and other feelings about camp. One interview question was modified during the UniversalTeens interviews: "If another kid (with HIV) was thinking about coming to this camp, what would you tell them?" The "with HIV" part of the question was problematic because that word was rarely used by participants due to the ingrained secrecy and sensitivity associated with it. Instead, I used alternate wordings such as "like you" if I was unsure how open the participant was about disclosing her or his status, or "who has what you have" if the participant indicated a higher level of comfort with using the words.

Nine camper interviews were conducted during UniversalTeens. After UniversalTeens, two additional questions regarding disclosure and future life plans were added to the interview guide (see Appendix F). These additional questions were added because after initial coding of the UniversalTeens data, there appeared to be connections between campers' level of confidence and willingness to disclose HIV status.

Additionally, some campers expressed plans for future careers that sometimes related to their camp experiences. However, due to the younger ages of the campers at Camp Hope (13-15 versus 15-19 at UniversalTeens), these new questions did not yield much useful information. Older campers were more concerned about their future and had more practice with educating others about HIV/AIDS; younger campers had less experience contemplating these issues.

Establishing trust during the interviews facilitated my being seen by participants as just another member of the camp staff, and they generally were receptive to camp staff due to the staff's perceived status as being supportive adults. It was also helpful to first interview those campers in Camp Hope who were considered "cool" in order to make it easier to establish rapport with them. The value of this approach was learned during UniversalTeens, when I interviewed more of the "outsider" participants early in the program, and left those who were cooler for later in the week; by the end of the week, attempts at meaningful interactions with the cool kids became awkward. Participants who had more of an outsider status had fewer social obligations and therefore more opportunities to talk with me, and it was easy to talk with them at any point during the program. In addition, they enjoyed the attention.

Based on my experiences during UniversalTeens, I sought to first interview those campers in my own cabin who seemed aloof and difficult to approach. This was done to quickly develop trust within the close living quarters of the cabin, and to try to prevent too much social distancing to happen throughout the week that could hamper later efforts at establishing rapport. It appears that this was successful. For example, while settling into the cabin on Sunday, the other counselors in my cabin expressed concern that one girl would not participate during camp; she stayed by herself, scowled often, and maintained a haughty attitude. After our interview which took place after lunch on Monday, this girl was much warmer to the other counselors and me.

Rigor in qualitative research required that I gather data until a saturation of findings occurred. Saturation is the point where nothing new emerges from collected data, and when findings have been confirmed through revisiting participants and interviewing new participants as needed (Guest, Bunce, & Johnson, 2006). Saturation of camper interviews occurred after the second interview at Camp Hope. At that time, a more specific approach was employed to target campers who had different experiences at camp due to being social outsiders, used wheelchairs, or lived in particularly tough home environments. These campers were selected after consultation with the camp director, a doctor, and two social workers. Two of these interviews yielded little information; these two campers (“Kevin” and “Milton”) had cognitive impairments that inhibited full understanding of the interview questions. I was unable to successfully adapt the interview questions to meet their needs. Nonetheless, the information I was able to gain from these interviews were included in the analysis. I felt that their voices



were an important part of the social fabric of camp, and should be represented in the findings, regardless of their ability to fully articulate their experiences.

### **Caregivers**

Members of this group were included in the study because they had extensive and long-standing knowledge of their children via daily, informal, and familial interactions, and could provide another perspective on the possible influence of camp within their children's lives. Specifically, caregivers could explain what changes they observed in the attitudes and behaviors of their children as a result of their children's camp attendance. Due to their maturity, caregivers could also reflect on outcomes that children do not or cannot report. The purpose of caregiver interviews was to explore caregivers' perceptions of their children's daily experiences and significant relationships, intentions when sending their children to camp, and what their impressions are of their children once they return home from camp (see Appendix G). It was hoped that this group would provide perspectives of campers in non-camp settings, and the possible influence of camp's supports and opportunities for the development of campers outside of camp.

An original procedural intention of this study was to conduct phone interviews with 10-12 caregivers. After discussion with the camp director, we felt that this method would be ineffective for gathering data due to the unlikelihood of caregivers returning my calls and participating in the study. The camp director felt they would not participate because they did not personally know me, or because of difficulty in accessing the Camp Hope population.

Next, the camp director and I made a plan for me to attempt to collect caregiver data via in-person interviews immediately before and after camp, while waiting for the camp bus to depart or arrive. However, it proved very difficult to gain access to caregivers in this manner. This difficulty arose from various factors. The drop-off setting and atmosphere was extremely loud and hectic, and there was no time or place to conduct private interviews with caregivers; they were too busy saying goodbye to their campers and signing forms. Given this hectic setting, plans were dropped to try to recruit caregivers at the end of camp.

A couple of weeks after camp, the camp director and I decided to send letters with a simplified version of the parent/caregiver interview questions (Appendix H) and a self-addressed stamped envelope to 25 caregivers that he identified as being good possibilities for responses. Nothing came back. The camp director was not surprised at my difficulty in recruiting caregiver study participants; social workers, doctors, and he have also had difficulty in communicating with caregivers due to their busy work schedules, problems with poverty- and health-related issues, and hesitation to talk to researchers due to fear and distrust of diagnosis disclosure and of the general medical establishment.

One caregiver interview did take place via email. A parent sent an email to the camp director commending him on the UniversalTeens program for her son. The camp director gave me permission to contact this parent via email to invite her to participate in the study. She requested that the list of questions be emailed to her, and she replied one day later with her answers via email. As this parent clearly held such positive feelings

about camp that she was motivated to contact the camp director to express herself, her inclusion in this study is made with caution, for it is very likely that she was not typical of all potential caregiver study participants.

### **Camp Staff**

This group was included in the study because they could observe changes in campers over time, and were able to address more specific in-camp processes that influenced these changes. Due to responsibilities of camper supervision and full schedules, informal interviews were easier to conduct than formal ones. During Camp Hope, one structured interview with a counselor took place the night before campers arrived; he was chosen due to being positively mentioned by several UniversalTeens participants and because he was not interviewed in 2007. One structured interview with the camp director took place on the second-to-last day of camp, and an informal interview was conducted on the night before campers arrived. Throughout the course of the week, informal interviews were conducted with four counselors, one doctor, and one social worker, and brief discussions held with the camp director for clarification purposes. Participants for these informal interviews were selected due to their convenient proximity to me, such as while we were watching campers participate in an activity meant only for campers, or while staff were on break and I happened to walk by and started talking with them.

### *Observations*

In addition to interviews, unstructured observations and artifact review were used to collect data. These methods were targeted towards gaining an understanding of the in-

camp processes that fostered supports and opportunities for camper outcomes.

Observations included a meeting with the camp director, psychosocial team, and medical team a week before camp, staff training the day before campers arrived, and participant observations during Camp Hope. Field notes were frequently taken during camp to capture experiences. Artifacts were collected before, during, and after camp. Below is more specific information about these data collection strategies.

### **Unstructured Observations**

During unstructured observations, field notes were taken during Camp Hope, employing use of thick description (Geertz, 1994). Two notebooks were used: (1) a small one for taking quick notes in the midst of experiences (such as quotations), and (2) one in which to record reactions, reflections, emerging themes, and possible explanations. Use of the notebooks was as discreet as possible, so that others did not feel self-conscious. Camp was fast-paced and exhausting, leaving little time within camp to take detailed notes; notes were primarily written before I went to sleep, during down time, and while others were presenting information or leading activities and I was a spectator. Some notes were dictated into my digital recorder while driving alone to or from camp. Of course, these observations were based on my own interpretations of events.

### **Artifact Review**

Examination of objects included websites, emails sent to counselors and other camp staff, gifts for campers, evaluations, surveys, training manuals, camper and staff forms, daily counselor logs, and schedules. I was alert to potential artifacts throughout

this study; a list and brief description of these artifacts are found in Appendix I. The purpose of observing these artifacts was to gain a behind-the-scenes view of camp processes, the intensity and breadth of the planning that occurs for camp, and the evolution of ideas about operating camp. Review of these artifacts after camp and during data analysis helped to trigger memories of camp processes. Before and after camp, several emails were sent from the camp director to counselors and to others associated with camp; relevant examples of these emails are found in Appendix J.

### **Data Analysis**

The data analysis had two parts. First, data from the summer of 2007 were coded, and themes were developed that related to the purpose of the current study. Next, summer 2008 interviews and observations were conducted, transcribed, and analyzed.

Atlas.ti software (Scientific-Software, 2007) was used to aid in coding and representing data and themes. This software was designed as a tool for qualitative data analysis, and allows researchers to link codes with a variety of qualitative data (such as text or pictures), search for patterns within codes, and develop themes from these codes that can inform conceptual models (Lewis, 2004). The researcher inputs the data, and then follows procedures for coding and theme development as recommended by Strauss and Corbin (1998) or others.

Grounded theory (i.e. emerging from within a context) was used as the procedural approach to data analysis (Henderson, 2006). It was *not* used as the approach to the overall study as advocated by Glaser and Strauss (1967). The grounded theory

approach to data analysis is an inductive, expansionist approach arises from interpretive social scientists “who believe that understanding and truth come from

1. multiple realities, relationships, connectedness, wholeness, and inclusiveness,
2. an emphasis on induction and grounded (emerging within a context) theory,
3. contextual processes that focus on meaning, and
4. subjectivity and perspectivity,” (Henderson, 2006, p. 25).

Grounded theory was not the intended *outcome* of this study; it was the *process* by which data was analyzed, as Henderson explains (2006, p. 178). The results of this study included an outcomes-processes chart and an interpretation of the case, and these were grounded in the data through analysis. Data analysis was iterative, interpretive, emergent, and grounded in the available data while remaining open to other representations of knowledge.

Analyses of focus groups, interviews, unstructured observations, and artifact review data followed analytic induction procedures as outlined by Strauss and Corbin (1998), and clarified for use in recreation, parks, and leisure research by Henderson (2006). The following processes were used to analyze the data (as suggested by Strauss and Corbin, 1998):

1. Interviews and field notes were transcribed
2. Data were microscopically examined, line by line, to develop initial categories and relationships between categories (p. 57)
3. Questions were asked and comparisons made to guide theoretical sampling and to consider the categories’ ranges of properties and dimensions (p. 73)

4. Data were open coded to identify and describe concepts related to the categories (p. 101)
5. Data were axial coded to relate categories to their subcategories on the level of properties and dimensions in order to integrate the structure (conditional context of the phenomenon) with the process (sequences involved in a phenomenon over time) (p. 123)
6. Data were selectively coded to integrate and refine the theory, and to identify the range of variability and theoretical saturation of its concepts (p. 143)
7. Data were process coded to identify sequences involved in the phenomena, and to trace the changes in structural conditions of these sequences (p. 163)
8. A conditional/consequential matrix was constructed to consider the relationships between macro and micro conditions and consequences to each other and to the process sequences, while considering contingencies (unanticipated events) (p. 181)
9. Indicators were theoretically sampled that represented relevant concepts, and their properties and dimensions were compared until categorical saturation was achieved (p. 215)
10. Memos and diagrams were developed to illustrate the relationships between concepts and create the logic model (p. 241).

Using these procedures, a story emerged that explained the issues involved in study participants' perceptions of camp processes and outcomes. The analytic procedure was more iterative than is represented in the linear steps above.

Analysis of themes was accomplished via a phenomenological approach which focused on the question “What is the structure and essence of experience of this phenomenon for these people?” (Patton, 1990, p. 69). This approach assumes that we can only know what we experience, that there is no separate objective reality for people. The purpose of using a phenomenological perspective was to capture campers’ experience of the phenomenon of youth development at camp.

Constant comparison was used in the analysis to generate a provisional theory of how camp processes related to outcomes for campers. Glaser and Strauss (1967, p. 105) suggest that there are four stages to the constant comparative method: (1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory. Data elicited from campers, staff, and caregivers through interviews, as well as from observations, were compared and contrasted to establish congruence or incongruence between these different groups and methods, and to see if the processes that influence campers’ perceptions of camp context seemed to be specific or general.

Rival chains of events and potentially spurious relationships were examined inductively by looking at other ways of organizing the data that could lead to alternative findings, and considering other logical possibilities of explanation that are supported by the data (Patton, 1990). Negative cases were explored with an open mind and reported in order to delineate the patterns of the findings.

Next I describe the specific steps involved in data analysis. After conducting the first few interviews at UniversalTeens and while still in the field, I recorded in my



research journal potential emerging outcome themes and program processes by which outcomes might be achieved through camp participation. I continued to record my impressions and possible themes throughout the entire study via my research journal and digital recorder. During transcription of the interviews conducted during UniversalTeens, I recorded a deeper level of emerging themes in my research journal. These themes were compiled into a rough draft of the tables found later in this document (i.e. Tables 5, 6, 7, and 8). During the interview process at Camp Hope, I continued to record emerging themes and began to compare and contrast different sources of data. While transcribing interviews from Camp Hope, I recorded my impressions in my journal. After transcriptions were completed, I refined the charts of the links between outcomes and processes over the course of several weeks while rereading the interview and observational data to confirm links and establish degrees of strength of the themes.

First I open coded for outcome themes and sub-themes. Next I open coded for process themes and sub-themes. During coding, it became apparent that the interview data yielded the clearest answers to the first research question: “What were the developmental outcomes experienced by youth as a result of attending camp?” The observational data yielded the clearest answers to the second research question: “What were the processes that facilitated youth development at camp?” Linking the outcomes and processes was intuitive, and relied on continual reexamination of the data to support and refine conclusions. Additionally, I discussed my initial findings with members of my committee and camp professionals to ensure that the links made sense.

During axial coding of both sources of data, I looked for evidence of processes within the interview data, and evidence of outcomes within the observational data. This constant comparison method resulted in outcome and process themes that were evident across all data sources. However, it should be noted that the strength of the evidence differed depending on the source of data and the research question. For example, campers typically reflected on how participating in camp influenced them (outcomes). Even though I faithfully asked probing questions such as *how* they experienced outcomes or *why* they said what they did, I received fairly narrow answers such as “because everyone here is so nice.” It is possible that the campers were not developmentally advanced enough to deeply reflect on camp processes. Future studies could employ a stronger means-end analysis approach that aims to discover how participants think about a certain phenomenon and the meanings they associate with it (Klenosky, Gengler, & Mulvey, 1999).

### **Outcomes of the Study**

The results of this interpretive case study included a description and interpretation of the themes associated with the two research questions, and an outcomes-process chart. In Chapter IV, I discuss the study’s research questions and study findings. Themes were consolidated and relationships between themes were explained in an attempt to answer the research questions about outcomes for campers and the processes within camp that are associated with these outcomes. In Chapter V, I discuss an outcomes-processes chart to articulate the relationships between within-camp processes and camper outcomes. Constructing such charts is often used in intervention

studies to identify the important program-level factors that are connected to outcomes for participants, and to describe a “theory of action” (Bloomberg, Ganey, Alba, Quintero, & Alcantara, 2003) in which theory, program components, and outcomes are linked (Baldwin et al., 2005).

### **Establishing Trustworthiness and Validity**

In any qualitative case study, but especially in studies involving young people, and most especially young people with HIV/AIDS, ensuring trustworthiness and validity (or credibility) of the data and interpreted themes are paramount concerns. I used several techniques to increase the trustworthiness and validity of this study.

First, Texas A&M University’s Office of Research Compliance, as well as AFH and CFA approved this study, and I closely adhered to the original intent and integrity of the study. Second, as discussed earlier, consent and assent from campers and staff were secured for study participation. Third, all participants were given pseudonyms, and identifying information of participants was removed or modified. Fourth, member checks were conducted with two camp staff and one camper. Next I discuss these procedures in more detail.

The trustworthiness of the findings was checked through several methods (Creswell, 2003). Triangulation involved the examination of campers’ experiences from the different points of view of their caregivers, staff members, and the campers themselves. These data were also compared with observations from the field. Member-checking for further refinement of themes occurred by sharing interpretations with the camp director, one staff member, and a camper, as well as with peers who had

knowledge of camps for youth with chronic illnesses. My biases that arose from my personal understanding and previous experiences were acknowledged and kept separate (i.e. bracketed; Gall, Gall, & Borg, 2007) in order to better understand the experience of camp from the point of view of the participants. Findings that appeared to be discrepant are examined and discussed later in this document.

Yin (2003) suggests that there are four tests or criteria for judging the quality of case study research designs: construct validity, internal validity, external validity, and reliability. Construct validity is concerned with establishing correct operational measures for the concepts being studied. This was accomplished in three ways: through the use of multiple sources of evidence; establishing a chain of evidence; and member checks.

First, evidence came from interviews, focus groups, and observations. Triangulation occurred through multiple data sources (campers, staff, and one parent), investigators (my advisor, interviewers, members of the case, and myself), theories (grounded theory, positive youth development), and methods (phenomenological case study, interviews, observations). Second, the chain of evidence was explicated so that an external observer could follow the derivation of the evidence from the research questions to the methods of data collection and analyses to the study conclusions. Third, I checked with the camp director, a counselor, and one camper to see if I had represented their experiences appropriately. These members felt that I had done so, and clarified the wording for a couple of minor outcomes and processes of camp.

Internal validity aims to establish causal relationships in which certain conditions are shown to lead to other conditions, instead of spurious relationships. An outcomes-processes chart was thus articulated as one of the results of this study to explain findings.

External validity establishes the domain to which findings can be generalized. In qualitative research, findings can be generalized to theory, while the sample cannot. As Yin (2003) suggests, case study findings can be generalized to theory, similar to how experimental results are generalized to theory. Known as “replication logic,” this suggests that if future case studies were conducted on similar camps, the theory could be tested and accepted for the larger number of similar camps, beyond the camp in the current case study.

Extensive and detailed documentation and adherence to case study protocol were employed to establish reliability. As a qualitative study, maintenance of integrity throughout the process was important. Following qualitative research guidelines helped to ensure this integrity. These guidelines specifically included: acknowledgement of researcher bias, validity assurance, triangulation, member checking, use of established protocols for participant selection and interviewing, and quality assurance in analyzing data and reporting findings (Yin, 2003; Patton, 2002).

### **Researcher Identity**

Due to my previous experience working with camps, I brought certain biases to this study. I attended camp for three years as a teenager, and found it to be an important support in my life which, at the time, was usually fraught with issues related to low self-esteem and poor peer relations. As an undergraduate, I worked as a counselor for three

summers at the local parks and recreation department's day camp. As part of my first full time job, I arranged for several of the participants in my outreach program for girls at-risk for poverty, drug use, and pregnancy to attend resident camp and supported their involvement during camp as various behavioral issues emerged. Later, I directed a camp for each of five summers, and another camp for one summer, interacting with over 1,000 campers and 250 staff members. Today, many of my close friends are camp directors.

These biases likely affected my study design, perceptions of the data, and subsequent analyses. Objectivity was attempted, but with the knowledge that it could never have been truly possible. At the outset of this study, my perspective of camp was that it was a positive developmental setting for youth. I viewed camp as a worthwhile experience in the lives of those who participate in it. All attempts were made to minimize this positivistic tendency. Specifically, my bias likely influenced the creation of themes and the outcomes-processes charts. However, I remained sensitive to, and informed about current literature on youth with disabilities (especially chronic illnesses, and most especially HIV/AIDS), as well as camp and other youth development settings. I also took steps to distance myself from the data by allowing time between readings, revisiting, re-wording, and discussing outcomes with my advisor and camp professionals, in an attempt to maintain an iterative process. Regardless, the themes and representations of findings are based on my personal lens, and I encourage other perspectives of the readers of this study to emerge.

Balancing the relationships between study participants and myself was important. In similar qualitative work, Michalowski (1996) suggests that there are four foci of the

relationship between the ethnographer and the ethnography: (1) the subject position of the ethnographer in the setting; (2) the privilege of the ethnographer in society at large; (3) the subject positions and agency of informants, and; (4) the location of ethnographic narrative within larger dominant discourses. These four foci are discussed below.

First, my subject position was one of training in the empirical tradition, influenced by Western ideals and values. Working in a system that is mostly structuralist, yet on occasion opens the window to poststructuralism, I tend to be concerned with labels, sorting, and linear processes. Class, race, ethnicity, age, gender, spirituality, ability, and sexual orientation were standpoints to acknowledge and I attempted to monitor their intrusion into data collection and analyzing.

Second, I had the privilege of access to both campers and other stakeholders (i.e. camp administrators, professors, youth developers), which necessitated a level of impartiality evidenced by not taking anyone's side and not judging anyone for their goals, beliefs, and experiences. This privilege of access was earned (through education and professional experience), and possibly unearned. For example, being White and having an upper-middle class upbringing could have provided me with instant respectability due to these demographic factors being privileged by many in our society. Awareness of this privilege and its potential influence (positive and negative) on various stakeholders in this study was at the forefront of all data collection and analysis.

Third, the campers have lived with their conditions for most if not all of their lives. They have taken medication, visited clinics, and been seen as "other." Many have been ridiculed, demeaned, and abused. And still, many have found creative ways to cope

with issues related to their medical condition, and fully participate in typical or normal experiences of childhood and adolescence. It was important for me to remember that a life can never be simply summed up as a life of struggle, or as a life of empowerment. My privilege was one of ability, not disability. While on occasion I was aware of my mortality during this study, thoughts about my health and ability took up very little time during the day; no medical condition or illness loomed over me.

Fourth, this study attempted to balance the views that (a) youth with HIV/AIDS are youth first with (b) youth with HIV/AIDS have a particular perspective in need of consideration. The hegemonic discourse in youth development is that programs should be tailored to the individual needs of the participants, while ensuring appropriate resource allocation to and within such programs. The tension between these views was considered throughout the study.

As a researcher, I negotiated several roles throughout this process. I was cognizant of how my past experience (especially directing camps) intruded into my analyses; specifically, criticisms of how camp “should” be run, and what camp “should” do for campers. For example, as I grew to know the camp director, my level of respect and admiration for him grew as well; should I ever direct another camp, I plan to incorporate many of his approaches and ideas into my own leadership style and programming. Emotions of pity or fear for the campers facing imminent mortality were processed outside of the interviews, and allowed to come and go. During this study I continually reflected on a major Buddhist precept that suggests that freedom comes when desires (such as the desire to save children) are allowed to come and go without



sticking. Buddhist teachers advise meditating students who begin to get carried away by thoughts and fantasies to simply label those thoughts as “thinking,” (Chodron, 1997) and to return to a focus on breathing in order to attain “beginner’s mind” (Suzuki, 2001). Using this technique, when judging or emotional thoughts emerged, I attempted to return to a focus on answering the research questions and staying present.

Throughout this study, I was reflexive about my outsider status (as an adult, as a person without HIV, as a new staff member) and insider status (as a general camp person). Such status provided me with power in one sense – I got access to campers for my study. It also limited my power in another sense – although my status did not allow me to truly experience what campers experience, the purpose of this study was not to communicate the truth, but to represent campers’ experiences (Cole & Knowles, 2001). Still, my personal biography was not dismissed throughout this process; rather, when my judgmental voice emerged, I reflected on those judgments within the context of the data and the goals of this study. As such, more emphasis was placed on outcomes of the interviews, and less on the process of the interviews; for example, linguistic data was not analyzed. I also maintained a research journal throughout this study to reflect on these issues.

### **Limitations of the Study**

As discussed above, there were two primary limitations to this study: researcher bias and inability to generalize the experiences of participants in this case to those in other camps, youth settings, or with or without other chronic illnesses. Additionally, this study was limited by the following related factors:

1. Potential ethical issues: Campers may have felt uncomfortable answering questions due to shame, fear, or desire for privacy about deeply personal issues and health concerns, even though trust and credibility were attempted to be established prior to the interviews. To attempt to guard against this, study participants were assigned pseudonyms to protect identities. Also, participants were reminded that they could discontinue the interview at any time without penalty.
2. Purposive sampling: This procedure decreased the generalizability of findings. The perspectives of youth who were first-year campers or physically unable to complete the interviews were excluded.
3. Convenience sample: This study used a convenience sample of campers and staff members who participated in UniversalTeens and Camp Hope who had consent from caregivers, and provided their assent to participate. Although theoretical saturation appeared to have been achieved, representation of the entire camper and staff populations cannot be known. Additionally, only one parent was successfully recruited for this study, and her perspective cannot be assumed to represent all caregivers of campers.
4. Self-report data: This study relied on the perspectives of campers and staff of their own attitudes and behaviors. The validity of these data is subject to threats from selection biases and systematic response distortion.

5. Validity issues: It is impossible to know how extraneous variables (i.e. the affect of the interviewers, peer influence on campers or staff, time of day, social desirability) might have influenced responses to questions.
6. Other interpretations: As in all research, the findings could be subject to other interpretations. It is possible that I misunderstood or misrepresented campers' standpoints, thus marginalizing and disempowering members of an already vulnerable population.

Even with these limitations, the findings have the potential to inform the youth development community, especially those within the organized camping profession and those who work with youth with chronic illness. Implications for future research to better understand elements of the programmatic context that relate to youth development also became apparent through this study.

## CHAPTER IV

### FINDINGS

#### **Introduction**

In this chapter, I present the results of this study by describing the case, then discussing the outcomes related to camp participation and the processes through which they occurred. Data for the case description mostly came from interviews with camp staff, particularly the camp director, as well as observations at camp and the review of artifacts. All study participants were assigned pseudonyms which were used in the findings and discussion. Additionally, camper participants from UniversalTeens are marked with (UT) and those from Camp Hope are marked with (CH). All staff and camp director data came only from Camp Hope.

#### **Case Description**

##### *The Organizations*

Camp Hope was a six-day residential summer camp program operated by AIDS Foundation Houston (AFH) at the Camp For All (CFA) facility, and began in 1996. Another AFH youth program, UniversalTeens (a six-day program) was started in 2006 when caregivers of some Camp Hope campers shared with the camp director that their children were actually not doing well after aging out of camp – they needed something to meet their developmental and educational needs during their transition to adulthood. UniversalTeens was created to provide support and opportunities for youth who were too old for camp but were not adults yet.

The following information about Camp Hope is taken from the AFH website (Retrieved September 6, 2008 from [www.aidshelp.org](http://www.aidshelp.org)):

For most children, summer is a time a time to play, to go to camp, to the beach, or on vacation a time to simply enjoy being a child. For children with AIDS, summer can be a lonely time, a time of staying indoors, taking medications, feeling sick, and experiencing isolation from friends.

In July of 1996, AFH launched Camp Hope, the first summer camp designed specifically for children ages 7-15 with HIV/AIDS in Texas. Participants now include youth from San Antonio, Dallas, Fort Worth, Galveston, Austin, and other Texas cities as well as from other states. Since its inaugural year, the camp has expanded from a three-day summer pilot program to a full-week program that has served [approximately 651 individual] participants over the last ten years.

These Houston children experienced a safe and fun-filled weekend without fear of stigma or discrimination... Camp Hope is so much more than just summer camp. Camp Hope offers the normal joys of childhood—joys that every child deserves. Most of these children live in households that earn less than \$700 a month and do not otherwise have the resources to attend Camp Hope.

More information about the backgrounds of campers, goals of camp, and processes and outcomes of camp will be covered in later sections of this chapter.

### *The People*

Several groups of people were involved in the operations of Camp Hope. The following chart highlights these groups along with their roles, focus, and other defining features and differences. Campers and staff will be discussed in greater detail below.

#### **Campers**

The campers in this study were participants in two AFH programs: UniversalTeens and Camp Hope. UniversalTeens was held at the University of Houston and served 19 participants ages 16-19 for six days in early June, 2008. Camp Hope served 143 campers for six days during late July 2008 at CFA. In both programs, most campers came from the Houston area, although about 40% traveled from other states (especially Florida). Camp Hope participants ranged in age from 6-16 with more participants at the upper end of this age range. Eighty-one percent were African American, fourteen percent were Hispanic, and the other five percent were biracial, white, or other (UniversalTeens participants were similarly distributed).

A doctor ("Dr. Helen") described campers' living situations as follows:

They have a wide variety of psychosocial backgrounds but a lot of them do not live with their biological parents. Either their biological parents have died from HIV, they've been taken out of the home for CPS [Child Protective Services] issues, they live with a grandmother, they live with an aunt - and so there's a certain amount of chaos in there. I don't know the other camps as well, but I would venture to guess that we have a higher percentage of kids from a lower socio-economic standpoint just because, again, that's where HIV is in the United

States these days. Sometimes camp is the only week that they get three square meals for some of these kids, not all of them certainly, but for some of these kids. Some of these kids come from really chaotic homes and camp is a really rare opportunity for them to be accepted.

In campers' home lives, there were frequent feelings of isolation and conflict, often based on HIV status. According to a camper, "Janelle" (CH), camp stands in opposition to that:

[Camp is] just fun. It's totally different from where I live. I'm not sayin' where I live is bad. It just where I live isn't very good. I live in Dallas and so I know that part. And at my house it feel like they put me down or they treat me different. But here they don't treat you different, they treat you the same as everybody else. And it's just different. I feel happy here. When I come here... At home I get upset all the time, like argue, and like very high voice with my stepmother. It's different. Here it's fun.

When asked what it was that lead kids to feeling positively about camp, the camp director replied:

I think it's, there's a level of care, and it's obvious care that a lot of these kids don't see from their daily lives. And I think it's one of the motivating factors where the kids really kind of pursue their social workers and health care providers to allow them to come back to camp. It's one of the reasons why we have such a high repeat level within our camper base. I think there's huge benefits from camp for this population. We have kids for example who find

techniques and the abilities to [take meds] while they're at camp and they never have before.

"Bobby" (CH) shared the following information about his home life. He was one of only a few campers who shared specific information about his home life with me; most others were vaguer about their home experiences during interviews, presumably due to a lack of connection with me, a relative stranger. Bobby explained:

My mama, my foster mom, she come talk to me, but it ain't like she goin' punish me. She just talk to me about, like when I get real emotional about it [having HIV], or my real house or something like that. She tellin' me some stuff that'd make me cheer up. Sometimes she'll let me and my brothers and sisters go out in the backyard, like we got a house with a backyard - it's like a shed but it's a house and it got beds and stuff and refrigerators and stuff. And me and my brothers go out there and talk about at our house, when we get grown, how old we've grown, how what we're gonna do already, like what we gonna do in the future....

'Cause my mom, she couldn't take care of us, and we got put in foster care. See, my mom got put away - she did drugs. I tried to help. When I'm grown, I'm a try to help her. Like they got a rehab place. And I'll help and talk to her and get her to stop. She told me that she already stopped. My aunt said she ain't really sure or not, but I believe my mom....

When I grow up I wanna be a counselor here for a while. Then go back to my hometown, get me a house and stuff, and then try to find my mom. I ain't got



ALL my brothers and sisters with me - some of them away. When I go back home I gotta find them, and get in touch with them with my caseworker. I can't see my mom 'cause her rights got terminated a long time ago. I can still see my dad but he lives so far away, I haven't seen him in 2-3 years. He used to let me go spend weekends down at his house and holidays.

Bobby's description of his home environment was echoed in other ways by other campers. For example, another camper had been in four different foster homes in four different cities within the past year; one home even changed his first name, but the next one changed it back. Every counselor seemed to have a story that particularly stood out about a camper's background or living situation. Such stories were told with a sense of humility, awe, and even pity - like war stories - and were used to highlight the need for camp in these kids' lives. For most counselors, the backgrounds of the campers were far removed from what they themselves had experienced.

Still, there were realistic limits to what camp can do, as one counselor "Jeff" acknowledged: "And ALL the love in the world is not going to undo 15 years of horrible life." While optimistic about camp being a positive influence in campers' lives, many acknowledged the limits of this influence given the unsupportive and unstructured home lives of most campers.

### **Staff Members**

Camp Hope staff members were volunteers, with the exception of the camp director who was a full-time professional staff member of AFH. Staff members included counselors, medical staff, psychosocial staff, support staff, and the camp director. Four

counselors were also Teen Talk facilitators. At Camp Hope there were 79 staff ranging from ages 14-57. They were mostly in their 30s and 40s. Sixty-three percent of staff members were White, fifteen percent were Hispanic, fifteen percent were African American, and the other seven percent were Asian, biracial, or other. Camp Hope's staff tended to be professionally employed (e.g., Southwest Airlines, Department of Education, Sysco Food Service, restaurant managers), and were typically older than those recruited by some of the other partner organizations that hold their camps at CFA. Staff members' lives had been touched in various ways by HIV/AIDS, either because they were *infected*, or *affected* by the disease through loved ones.

### *The Setting*

The purpose of Camp Hope was to provide a recreational experience with caring people to youth with HIV and AIDS at the CFA facility in Burton, TX. This was enacted through participation in various activities such as swimming, bicycle riding, crafts, and other traditional camp activities. Additionally, an educational program called Teen Talk was conducted each night for campers ages 12 and older who were aware of their HIV status; the purpose of Teen Talk was to educate the campers on HIV and related issues. Participants included 143 youth ages 6-16, 9 support staff, 14 health care providers (including 5 doctors), 5 social workers, 7 counselors-in-training (CITs), and approximately 54 counselors. Each cabin had 7-12 campers with 3-4 counselors (one of whom was designated the Lead Counselor); there was one CIT assigned to each of the youngest cabins. Each cabin was a member of a cabin group which consisted of four cabins of similarly aged campers. Visible Camp For All staff included two program

directors and 6-8 staff members who conducted specialized camp activities with the campers. Other CFA staff members such as secretaries and the camp director were on site but not readily apparent. Table 2 describes the types of people in camp and further information about their roles.

The program was held in late July 2008 and began on Sunday and ended on Friday. The theme of the 2008 camp was “Camp Hope: An Olympic Event” in honor of the 2008 Beijing Olympics. Staff members arrived Saturday to go over the schedule and individual camper needs, get acquainted with the CFA facilities, and decorate the cabins. Most campers arrived by bus early Sunday afternoon; campers from Florida arrived later in the afternoon. After unpacking belongings and putting on the nametags they would wear all week, the cabin groups went on a scavenger hunt to become acquainted with the CFA grounds; due to the heat of the late afternoon and lack of available water, this activity was cut short by the counselors. Returning to the cabins, the counselors and campers got to know each other and decided which “pick-its” the group wanted; pick-its provided the opportunity to request an activity more than once. After dinner, a pool party was held and watermelon was served. Junior Teen Talk was held in the Gathering Hall for campers ages 12-13, and Senior Teen Talk was held in the Chapel for campers ages 14-15. Campers returned around 11:00 p.m. and lights were turned out at 12:00 a.m.

Table 2: *Stakeholders Chart for Camp Hope.*

	Medical	Psychosocial	Camp Director	CFA Staff	Teen Talk (TT) Facilitator	Counselor	Camper
<b>Role in camp</b>	Provide medical assistance and meds (6200 doses/wk)	Provide conflict resolution	Oversee all aspects of camp, work with CFA	Conduct activities with campers, enact what camp director (CD) requests	Facilitate TT, educate campers about HIV	Supervise campers	Participate in activities
<b>Role in planning</b>	Cabin placements	Cabin placements	Strongest, based on recommendations from others, very transparent	Based on what CD requests and what is available	TT only; has evolved through years to become stronger	Make suggestions about activities	Provide feedback on activity preferences
<b>Information owned and shared</b>	Medical info, treatment info, long-term relationships with campers	Family issues, at-home behavior issues, long-term relationships with campers	What medical and psychosocial teams tell him, counselor training and email communication	How to provide accessible activities	Common concerns of campers, give info to social workers; HIV info	Get a little background on campers from info sheets, describe in-camp issues to PS; give meds	About self, about others in social context
<b>Power</b>	Medication times and methods, treatment plans, emergency response, who gets to come	Sharing info with counselors about at-home issues, long term relationships with campers, who gets to come	Ultimate decision-maker, sets tone (mostly)	Activity offerings, within-activity decision-making	Over content of TT; seen as elevated status over other counselors	Over cabin atmosphere, follows the plans others make	Over self
<b>Values</b>	Illness management	Behavior management	Smooth operations	Safety, service to partner agency	Accurate info based on camper needs	Fun, belonging, gain perspective	Fun, belonging
<b>Goals for self</b>	Understand campers better	Provide support when problems arise	Make things better each year	Quality programming; fun and challenging activities	Provide open and safe space for questions and learning	Feel like they're making a difference; provide fun time	Relax and have fun, meet similar others

Table 2 Continued.

	Medical	Psychosocial	Camp Director	CFA Staff	Teen Talk (TT) Facilitator	Counselor	Camper
<b>Goals for campers</b>	Medication adherence	Behavior improvement	Stop cycle of poverty through education and exposure	Love, laughter, hope, healing	Education, med adherence, connections (decreased isolation), skills	Fun, relaxation	Relax and have fun, meet similar others
<b>Selection of campers</b>	Not medically fragile, compliant with treatment plans	Compliant with clinic visits, manageable anger issues	Willing to be there and open to change	None	It's optional to attend TT (most attend)	None	Through behavior
<b>Chosen by</b>	Partner clinics	Partner clinics	AIDS Foundation Houston	CFA Camp and Program Directors	Camp director – based on out-of-camp roles as HIV educators and longevity with program	Word-of-mouth, tradition	Doctors and social workers from clinics
<b>Alignment issues</b>	Fun comes a distant second to med adherence	Look for problems to solve	Education/ knowledge/ skills/ attitudes goals not shared by counselors, sometimes at direct odds	Don't necessarily know campers or "get" the population	To campers and some counselors, education is not primary reason why campers come	Personal goals over camper goals (some-times)	Aging out

Certain activities took place Monday through Thursday. These included early morning fishing from 7:15-8:00 a.m., breakfast from 8:00-8:45 a.m. followed by morning aerobics and the Camp News Network announcements. There were three morning activity slots of 45 minutes each. Activities included: sports, arts and crafts, bikes, canoes, fishing, high ropes, horses/barnyard, drum circle, parachute games, archery, paintball, basketball, softball, kickball, and cooking. Arts and crafts and cooking were conducted by a Camp Hope support staff member; the rest were facilitated by CFA staff. Lunch was 12:00-12:45 p.m, followed by rest time in the cabins for one or two hours (younger campers had two hours rest). Canteen was held for thirty minutes in the basketball pavilion during which snacks were served and campers informally socialized or played basketball.

Afternoons consisted of 1-2 hour long pick-it activities and free swim. Dinner was held from 5:45-6:45. Evening activities changed each day, and were completed by 9:00pm. Junior and Senior Teen Talk sessions were conducted separately until approximately 11:00pm each night. While both sessions dealt with factual information about HIV transmission, immune systems, viral loads, condom use, and disclosure, Junior Teen Talk was more basic than the Senior Teen Talk. Lights out for all cabins was midnight. While this schedule was generally adhered to, there were daily variations which are discussed below.

Monday's special activities included Glamour Shots (dressing up and taking pictures), a campfire for younger campers, and the Black Light Party (music and dancing with glow-sticks and ultraviolet lighting in the Gathering Hall) for older campers. On

Tuesday, a Lead Counselor meeting was held during lunch in the Art Barn to discuss and troubleshoot issues. On Tuesday night, Senior Teen Talk was held immediately after dinner so that the older girls could watch a movie and eat popcorn in the Gathering Hall while the boys went on the zip line of the ropes course in the dark, using glow-sticks and black lights. Younger campers had a sports night, and then Junior Teen Talk was held.

Wednesday was Visitor's Day and the entire camp wore their Camp Hope 2008 t-shirts. Each year, AFC invites donors and other friends of Camp Hope to visit camp for a few hours to see the campers and the activities. After lunch, the Camp Hope Olympics were held in which campers competed in potato sack races, water balloon fights, group relays, and other games. However, it remained very hot and campers were quickly exhausted (especially given that this was the fourth day of camp), so most cabins retired to their cabins for extra rest time after an hour and a half of participating in the Olympics. After dinner, CFA facilitated the Olympic Idol Talent Show in which campers sang songs and danced; they were given scores by "judges;" however, there were no winners. Due to several older campers "melting down" with psychosocial issues, Senior Teen Talk was cancelled that evening.

Thursday morning was "Water Day" which entailed round-robin activities facilitated by CFA staff such as water relays, water balloon obstacle courses, and other games to get campers and counselors very wet and muddy. Surprisingly, it was relatively cooler that day due to a storm front from a gulf coast hurricane, so the need for cooling down was less acute than in previous days. In the afternoon, girls had their makeup done by representatives of MAC cosmetics while the boys participated in another pick-it

activity. After dinner, a DJ-led dance party was held in the Dining Hall, and a fireworks show was conducted in the fields of CFA. Instead of Teen Talk, cabin groups held “after parties” or “raves” back at the cabins that included snacks, dancing, and socializing.

On Friday before breakfast, all campers and counselors packed up their belongings and the cabin decorations – these were delivered to the parking lot by CFA staff. At breakfast, memory books (alternatively called yearbooks or weekbooks) were distributed to campers and staff, and campers spent approximately 30 minutes writing messages in each others’ and staff members’ books. Groups of campers were loaded onto the buses based on their home destinations. The staff members formed a double line outside the dining hall that led to the bus, and clapped and cheered for the campers as they walked to their buses. After the final bus left, the staff members met in the dining hall to debrief, thank each other, and evaluate the week. The camp director shared that the theme of next year’s camp would be “Holidays” and assigned specific holidays to Lead Counselors such as birthday, St. Patrick’s Day, etc. After this, most counselors departed CFA to go to Applebee’s in Brenham for drinks and lunch. I experienced a difficult sinus infection and went to a health clinic instead of Applebee’s.

Several staff members commented on overall camp issues throughout the course of the week. For example, the increased presence of psychosocial staff previous years seemed to result in fewer behavioral problems [still, one camper was sent home due to continued resistance to behavior modifications]. Other staff members were upset with the lower levels of cleanliness and involvement of some CFA staff. Most felt their campers were more rested than in past years due to greatly increased rest time



opportunities. A couple of weeks after camp, the camp director emailed an online survey to staff members to obtain input and further evaluation of activities and camp; results of the survey were then emailed to staff members.

### **Outcome Themes**

One of the two research questions for this study was “What are the developmental outcomes experienced by youth within camp?” This section identifies four outcome themes identified during data analysis: (1) experiencing caring people, (2) developing a sense of belonging, (3) feeling reprieve and experiencing recreation, and (4) increasing knowledge, attitudes, and skills. These themes were selected because they were all mentioned in varying degrees by all study participants in their interviews. Additionally, indicators of these four themes became apparent through my observations during camp.

The four themes were strongly linked together and were not discrete categories; rather, they were nested within each other in a temporal order. When campers experienced caring people, they had a sense of belonging. These two relationship-based outcomes opened a space for feelings of reprieve (from responsibilities and stigma at home) and recreation (to engage in fun activities) at camp, and this relaxed space provided an opportunity for the development of knowledge, attitudes, and skills.

The importance of relationships in youth contexts has been demonstrated in virtually all research conducted in youth development (e.g., Anderson-Butcher, Cash, Saltzburg, Midle, & Pace, 2004; Grossman & Rhodes, 2002; Paisley, 2005; Scales, Benson, & Mannes, 2006). Programs are driven by the relationships contained within. In

this study, campers' feelings of reprieve and recreation, and increased knowledge, skills, and attitudes were largely predicated on caring relationships with individuals and the camp community. The first three outcomes (caring people, sense of belonging, and reprieve and recreation) additively contributed to the last outcome (increased knowledge, skills, and attitudes). It is very likely that those campers with fewer or more frail social connections also experienced diminished outcomes in feelings of reprieve and recreation and in skill, knowledge, and attitude development. Given that these outcomes were nested within each other, it is likely that diminished effects in one outcome area influenced other areas. Conversely, strongly positive experiences in one outcome area likely positively influenced other outcome areas.

Table 3 highlights the outcome themes and the sub-themes of which they are comprised.

Table 3. *Outcome Themes and Sub-Themes.*

Outcome	Sub-Themes
Experiencing caring people	The social context of camp is caring Campers are caring at camp and outside of camp Counselors are caring at camp People from camp are encouraging Campers are not judged
Developing a sense of belonging	Campers feel isolated at home Campers are around similar others at camp Camp feels normal, like a home
Feeling reprieve and experiencing recreation	Camp activities are fun Camp is something that is anticipated and reflected on all year There is a sense of freedom at camp

Table 3 Continued.

Increasing knowledge, attitudes, and skills	In the domains of: Anger and conflict management Confidence Disclosure attitudes and skills Learning and education Medication adherence Hopefulness Personal growth Other outcomes (self-esteem, finding dating partners, thinking of others before themselves, structure)
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### *Experiencing Caring People*

The content analysis revealed a pattern of participants experiencing caring people through the overall social context and interactions with campers and staff. Through these caring experiences, feelings of support for coping and of not being judged were evoked. The theme of “Experiencing caring people” was comprised of five sub-themes, which are discussed below.

#### **The Social Context of Camp Is Caring**

This category describes how most campers and staff felt that the overall social atmosphere of camp was caring and supportive of them. The camp context was favorably compared to other contexts in the lives of campers and was often listed as a top reason why camp is so memorable: “The most memorable experiences are like, when you come here it’s fun ‘cause you’re around people who has the same thing as you, and ain’t nobody gonna come against you unless it’s about something else” (Janelle). “Rachel” (UT) shared that “At camp people with HIV can talk to each other. My family

doesn't care, but camp cares. It's different for [HIV] negative people - they're not given support when they have problems. Camp makes time for people with problems."

Campers had numerous examples of specific one-on-one and small group demonstrations of caring for them. A caring social context was also evidenced in large group settings as well. "Nelson" (UT) described significant camp experiences during the all-camp Talent Show that continued to resonate with him:

And it was my first time singing it ["The World's Greatest" by R. Kelly], so I was like "ok, I can just do it" and everyone was crying, happy, and everything like that. And then the next year I sang it again and everyone expected me to sing it so I did it, and "Larry," which is one of the counselors there, he came down later. He ran up on stage and had a cape and put it on me and disappeared, like Spider Man, just like disappeared. I was like, ok, just started singing and everyone started crying 'cause it was my last year and everyone started chanting my name and it was a good feeling, like a really good feeling.

The camp director also discussed the influence on campers of the camp's caring social context:

I think it impacts the campers because it hopefully allows them the knowledge that a) there are people who care about them and that b) there is a life and it's not maybe as *glim* [grim or glum] as they either felt or have been told by others.

### **Campers Are Caring at Camp and Outside of Camp**

Participants expressed how campers felt cared for by other campers. This caring occurred within camp through social interactions, and outside of camp through phone

calls and electronic messaging. For example, during UniversalTeens, one young man had trouble walking and climbing up and down stairs. His close friend stayed with him, often far behind the rest of the group, and helped him with stairs. This young man was also very quiet and watchful during the program, but when he did speak up, the entire group would quiet down to intently listen to his insights and sharing of deep feelings.

Experiencing caring campers was often most strongly evidenced within the context of support for grieving. Jeff, a counselor, relayed the following story about a group of boys in his cabin:

I mean the kids are incredible, it's just amazing what they're capable of. (Like what?) Just, again really the boys, they all act REALLY tough. And, but, they, I've seen them just come through for each other, and it's just really incredible. I mean, I had one camper in the past, his mom had died literally I think 2 weeks before camp. He didn't want to be here, his family made him go. He had always gone to, what is that other camp? It's a national camp for kids with HIV.

Anyway, he had supposedly gone to that, and for whatever reason he couldn't go. And so they sent him here, and it was literally TWO weeks. And we struggled. He was non-communicative, wouldn't talk, wouldn't look you in the face. And it was really hard to know what's happened here, at the same time - the one kid in the cabin who's NOT participating, who will drag everyone down. It was just really tough. And he finally said something [about his mom to the counselors], and of course we couldn't tell the other campers about it. He finally said something to one of the other campers. And we had this huge meltdown scene

and he stormed off. And literally the guys did like an intervention. TOTALLY on their own. They went in, each one of them shared their story of how they lost a parent and how hard it was. Totally changed the rest of camp, he was a different kid. And the whole cabin, it was just incredible. These 14 year old BOYS. It's amazing.

“Ashante” (UT) shared that her friends in her cabin needed to express their feelings about the death of a fellow camper:

One of my counselors told us we could stay up as long as we want as long as we get up in the morning, if we don't make that much noise. So we went in the bathroom and we was talkin' about it or whatever, and we was gettin' our feelings out and crying about it and stuff, but it *helped* us.

Campers also felt cared for by other campers in other situations such as when being given advice about dealing with various issues, and simply being listened to.

These relationships between campers continued after camp as well, through phone calls and text messaging. A camper's parent described these relationships as

Long lasting. I still remember the first phone bill after camp. Let's just say "text messaging" wasn't my friend financially. He wanted to take vacations to other states to spend time with some of these kids. If only adults could bond like these kids do.

There were some negative cases within this category. About fifteen percent of the campers referenced situations where they had disagreements with other campers (or “drama”). Janelle described this type of negative social interaction as follows:

My friendships with other campers - it's fun but to tell you the truth, I haven't been in every cabin and sometimes I might not like another camper and there's drama. But if there's drama in the cabin, we won't let it, we won't tell that person 'cause that would make more drama if it was like their best friends or close friends.

In another situation, a young woman in our cabin was talked about behind her back by a group of other campers; they believed that she was unaware of her sexual orientation as a lesbian and tried to guess when she would figure it out; while this did not seem to be done in a supportive or caring manner, there were no indicators that the girls were panicked about it either. After this incident I did not observe the group distancing themselves from her in any way; she remained an included member of the group.

### **Counselors Are Caring at Camp**

Campers in particular discussed their feelings of caring that they received from counselors. Caring from counselors appeared to be shown through counselor role modeling and being approachable. Long-term relationships helped to cement these perceptions of counselors as caring. For example, "Devin" (CH) who struggled with behavior issues at camp wanted to be like his counselor "'cause he's in college and he thinks about books before girls, and he's a nice guy."

Some campers described how the counselors role modeled appropriate activity participation:

In morning aerobics, some of the other kids, they were like not dancing, but I was noticing that the counselors were like "oh you should do this, you should do

that, come on let's dance! Let's wake up!" 'Cause sometimes I get tired of doing the right thing. But they turned it up: "you need to dance!" (Ashante)

Most campers discussed how approachable the counselors were, "like a big mommy and daddy" ("Sean," UT). Counselors were seen as being people they could talk to (regardless of counselor HIV status), who would be on the "downlow" with campers and willing to "call them on their shit." Most importantly, they were seen as having "an open heart," wanting to hear what campers had to say, and being concerned with their well-being. Some campers mentioned how impressed they were that the counselors were all volunteers who gave up their time to work with them.

Counselors also reflected on their roles with campers:

Jeff: I really think we're here to, I see myself as here to facilitate. I think that's really it.

Me: Facilitate what?

Jeff: Those interactions, to give them more opportunities to, to allow them time to, like reign in, to guide, to sort of steer as much as possible. That sounds so official, like a cop-out [laughs]. I think honestly that's what we're here for. In some ways to be there and make sure the kids get to activities on time.

Me: But that's not all?

Jeff: No, no. But I think there's something to be said for letting kids know you care about them. All of that, so that they DO know there are people out there if no one else.



However, sometimes counselors were considered to be caring for other reasons; one focus group participant explained that “When we all leave the cabin, they put bags of toys and stuff on our bed.” In addition, counselors seemed adept at cheering up some campers by being funny, or distracting them with fun activities. And, three of the campers were unable to describe any particular counselor: “I can’t. ‘Cause they’re all equal, they all the same, they all gave me HOPE” (“Breshawn,” CH).

While campers’ regard for counselors was almost universally positive, there were a couple of instances when campers described negative interactions with counselors. In one of the girls’ cabins, there was dissention between the counselors that seemed to be noticed by the campers. One camper in particular was mad at the Lead Counselor; she was defiant towards the counselor’s attempts at guiding her behavior, and the situation seemed to snowball throughout the week so that the two remained in constant conflict. Additionally, during a focus group, a group of boys discussed their feelings about their lack of connection to some counselors:

I only like one staff in my cabin, “Robbie.”

Focus group facilitator: Why do you like Robbie?

He’s the only one that’s straight.

Facilitator: What don’t you like about the other ones?) They go both ways. I do like two staff. I like “Kevin.” They need to start mixing up staff, make them play some manly sports.

During the Sunday night pool party, I observed several staff standing around “like it was a cocktail party,” and not interacting with campers; rather, they stood off to the side of

the pool and socialized amongst themselves. This may have been influenced by the lack of training given on how to interact with campers, counselors' lack of experience with young people, or the prevalence of cliques within the counselor group.

### **People from Camp Are Encouraging**

Campers face many different issues in their lives, and all discussed how people (both campers and counselors) were encouraging to them in specific tasks as well as provided support for coping with HIV. These interactions took place within and outside of camp. Campers frequently mentioned how encouraging people were during the high ropes course activity as they struggled to overcome their fear of heights. Outside of camp, Breshawn discussed her fear of taking a standardized math test, and calling her camp friend for support: "She like 'You can do it. Like Camp Hope says, you gotta have hope in yourself, you gotta have faith.' I like [with hesitation] 'ok.' We started laughing. She said 'I for real!' I said 'I know you for real, that's what's funny!'" And she passed the test for the first time.

The idea of encouragement was also more generalized beyond a task to helping campers cope with HIV:

At school, it's like people telling you what you have to do, and you have to do work. And not that work is bad 'cause work helps you be stronger. But at camp you just always get a pat on the back...You're just always getting reassured that it's okay that you have this, and it's just a good feeling. ("Cece," CH)

Jeff also shared the type of encouragement that he, as a counselor, wants for campers as they grow up:

I want them to grow up supported, I want them to grow up healthy. Um, I want them to grow up in an environment where they're encouraged, that they're allowed to make mistakes, that they can learn and grow and be themselves, and have room to screw up occasionally. So that they become adults who are well-rounded, who are *great*.

Encouragement from trusted others was seen as a type of support for coping with life's difficulties.

### **Campers Are Not Judged**

At home, campers experienced frequent real and perceived feelings of being negatively judged and put down by others based on their HIV status. At camp, there was an absence of judgment: "...y'all look at us as what we are. Y'all look at us as regular human beings, like special kids" (Breshawn).

One of the reasons given for this feeling of not being judged was that at camp, everyone dealt with the same issues related to HIV:

...we all have that thing in common. It makes us all more at ease because we don't have to, we're not judging each other. Even though that everybody always judges outside of us [the campers]. E'rybody judges. But here, it's like, we're all the same, we're very complex at the same time. Very complex. ("Alison," UT).

"Raini," a counselor, shared her perspective of how campers are free from being judged at camp:

I think they realize that they don't have to be tough or this sort of personality that they've learned to be back home. There's nothing to hide from out here, they can

just sort of open up and nothing is going to happen to them, like they're not going to be made fun of, they're not going to be ridiculed or whatever. They feel safe here and so once they realize that this is an area where they can feel safe and that we're trying to help them feel at home here then that is really what helps them out.

To campers, caring people were those who did not judge them. When campers experienced caring people, they felt a sense of belonging to something good that was bigger than them. The relational support and consideration given within and outside of camp to campers assured them that they were cared for, which was sometimes considered unique or surprising given the lack of support and care in many campers' home environments.

### *Developing Sense of Belonging*

Participants reported feeling a sense of belonging to a larger, positive social group through camp. Through these experiences, feelings of a lack of isolation at camp, positive feelings about being around similar others, and descriptions of camp as being "normal" and "a home" were evoked. These patterns made "sense of belonging" a major theme of outcomes associated with camp experience. One quote from a male camper nicely demonstrates how campers felt the effects of a sense of belonging while at camp:

At home I'm like Clark Kent... But like here, I'm Superman. I'm just like, I'm more open, more talkative, more inspired... 'Cause when I'm at my home it's like I'm hiding from everybody else. And that's sad because I don't want to, but it's

like I'm in the phone booth and it seem like I can't even be around you, so, I just don't communicate...camp is more open, it's just friends all over. (Sean)

A CFA staff member remarked that at camp, kids felt that they were a part of something bigger than themselves, and that that was a particularly valuable feeling for youth with disabilities and chronic illnesses. The theme of “developing a sense of belonging” was comprised of three sub-themes.

### **Campers Feel Isolated at Home**

Campers reported many instances of feeling alone and isolated at home due to the stress of hiding their HIV status for fear of the negative impacts of disclosure. All but two campers indicated varying degrees of needing to live a double life because close friends at home were not aware of their status. Even when others did know a camper's status, there remained a lack of a support system for sharing information and concerns about living with HIV/AIDS.

Generally, campers felt isolated at home, but at times it was unclear if that was due to the nature of HIV, or due to being teenagers. Jeff, a counselor, explained that

The problems most of these kids have in general, are the same problems that most teenagers have, they're just a little more complicated. I think most teenagers think “oh my God, I'm the only one in the world!” And so it lets them know they're not and that other people are going through this too.

Campers who had disclosed their status to others often found that their friends were just too uncomfortable to discuss it with them, due to pity, fear, or disdain. Ashante explained:

They cool with it, but they, like when I tell them about it or whatever, they like just, like “why you bring it up? Why you wanna talk about it?” And I be like “ok, time for another subject.” Up here, like my friends in camp, we talk about it. And we tell each other what’s on our minds, and get it out there, get out the stress about it.

One reason that campers felt isolated at home was because they took medications, and their friends typically did not. Campers seemed to have various strategies for maintaining their cloak of secrecy including hiding medications or explaining that the medications were for something else (such as allergies or anger management).

Me: How does camp let you be you, or does it?

Cece: ‘Cause you don’t have to like worry about, like usually if you have a friend that comes over to your house you have to go in another room and take your medicine and have to worry about explaining to another person who asks about why you taking your medicine. You have to lie and stuff. But here they already know, and everyone’s relaxed and you don’t have to worry about ANYthing here, it’s just, you be you.

Campers also expressed some “existential anguish” about why *they* had to deal with HIV, why *they* were chosen to have it, why their siblings did not have it. The camp director explained that

We want our kids to know and truly understand that they’re not alone. And they’re not alone because they’ve got the support of others. And from not alone

that they are not the only one dealing with this issue, there are others. All too often we will get, as the kids become older they'll verbalize "Why did this happen to me? Why me? It didn't happen to my brother, my cousin. Why me?" So they really need to have that reassurance. And I definitely think our counselors do that.

This anguish also appeared to be an emerging issue at camp: it was discussed within Teen Talk, and was identified by some Teen Talk facilitators, doctors and social workers as something that needed to be dealt with in the clinical setting as well as in future Teen Talk programs.

### **Campers Are Around Similar Others at Camp**

In contrast to the isolation felt at home, while at camp, campers felt that they were with others who were the same as them. There was no need for hiding because everyone knew each others' most closely-held secret, and campers could easily share information and support about living with HIV/AIDS. At camp, there was no need to "shapeshift," or to align one's presentation of self to match the context; rather, at camp, campers' identities could be more integrated.

Besides having HIV, the other major commonality between campers was the fact that they needed to adhere to a strict medication regimen. The caregiver participant in this study shared that for her son, "It was good for him to be with children like him that took medication on a daily basis. I wanted him to know that there are other kids like him and he wasn't alone." The camp director mentioned how campers felt connected with similar others because they saw 142 other campers taking medications right alongside of

them. Campers also discussed how they often learned more effective ways to take their medications, and how to deal with side effects from others taking the same kinds.

Having HIV could create a bond with another person who is positive, as “Matt” (UT) explained:

That’s what I LOVE about HIV. Because the community is SO large that you really just feel like one big family. ‘Cause you know, there’s always the [guy sounding sad] “Aw, man, I’m HIV positive.” [Matt sounding excited] “Dude, me too! Let’s go out, let’s go get some coffee, let’s get to know each other, you know, hang out.”

Campers also discussed how being around similar others was generally helpful to them:

It’s like um, like random conversations such as like what’s goin’ on in your life, and what’s goin’ on, what can camp inspire to you to make it so you have a *better* life. So we sit there and talk about it, and talk about how everything going in your school and all that. Everybody’s just sittin’ expressing themselves. (Sean)

At camp, campers felt understood by others, and this encouraged them to express themselves. Recognizing that life was more than having HIV/AIDS, Cece commented that

Like it’s better having a friend from camp ‘cause they just know everything about you already and they just know your secrets so you don’t have to worry about nothin.’ So if they already know that, it just feels that you can tell them anything else.

“Karen,” a social worker expanded on this idea:



I think most beneficial is, from talking to the kids, what they say is most beneficial is really just time together. They really don't care what they're doing, they say 'I don't care if it's bowling, or barbeque', it's just unstructured social time together where they just have the face time with each other and can hang out and relax and see each other and catch up with each other just for that support.

### **Camp Feels Normal, Like a Home**

Campers felt that the way things were at camp was how things should be everywhere in their lives, and that at camp, life was normal, whereas elsewhere, life was not normal. Devin referred to camp as "HIV heaven." The normality of camp was preferred, and this felt like home to most campers. Another camper, Alison, shared that

[Camp is a place where] I feel it is my home outside of home...Certain times here, just in camp in general, I feel at home more *there* than at home. Because at home, I pretty much to myself, I pretty much sheltered, I'm not really distant, I'm just mostly by myself all the time. But at camp, it allows you to interact with other people, and build relationships, and then they carry on throughout your life if you CHOOSE to do it, keep in touch with that person. I feel sometimes, I feel too comfortable here, this is my home. Or it's like, the next step from home.

The conclusion of camp was a trying time for some campers who wanted to stay at camp instead of going home and dealing with people and situations they do not like. The "camp family" was preferable to their at-home family. Related to feelings of being at home were feelings of being normal at camp. As the caregiver explained, "He's normal. He's excited. He's fits."

However, there were some campers who did not experience this sense of belonging. One camper discussed how he still felt different from other campers, even though he knew how similar they were. Two male campers were constantly picked on or ignored by other boys; for them, their sense of belonging arose from connections they had with counselors, not other campers. Finally, fifteen year old campers had a special status at camp as being the oldest campers; their sense of belonging to the camp community was the most ingrained and developed, and this status was formally recognized during a graduation ceremony. Regrettably, an administrative mistake was made prior to camp and replicated during camp that provided counselors and the organizers of the graduation with the wrong information about their ages. When names were called during graduation, about 15 campers were passed over because records indicated they were 13 or 14 years old. This created much resentment and anger among these campers, and they actively voiced their disappointment at the unfairness of this mistake that called into question their status and position in the community.

When campers felt a sense of belonging to a positive, accepting community that cares for them, a space was created in which campers became more open to trying out new ideas, activities, and attitudes. Connections with similar others and a lack of isolation brought up feelings that camp was home, and that the social context of camp was normal. In these connections, campers felt free of the need to hide in the phone booth and got to be Superman, their super selves. In this relaxed state, campers more thoroughly enjoyed the recreational activities camp had to offer.

### *Feeling Reprieve and Experiencing Recreation*

Data analysis revealed a pattern of participants reporting that while at camp, they had a reprieve from the stresses of everyday life, as well as opportunities for fun recreational activities. Camp provided leisure experiences for campers in that they experienced freedom *from* responsibilities and the need to hide at home, and freedom *to* engage in fun and challenging recreation activities. These patterns made “reprieve and recreation” a major theme of outcomes associated with the camp experience. Three sub-themes comprise the theme of “feeling reprieve and experiencing recreation.”

#### **Camp Activities Are Fun**

Campers spoke at length about their enjoyment of the fun activities at camp. Activities were fun because they were exciting, relaxing, novel, or interesting. They were also fun because they were available and accessible to campers. A camper, “Carl” (UT), described rules in camp as compared to rules at home: “I mean, it has its rules, but they don’t really care if you do the activity or not as long as you’re having fun.”

Additionally, the activities were platforms for social interactions. Camp was seen as a place to enjoy oneself, to participate in activities that they normally would be unable to do at home due to lack of availability or accessibility (especially for those with mobility impairments). Engaging in social relationships was also seen to be fun, and took place within the context of activities such as swimming, and informally within unstructured time in the cabins or during meals. Campers learned how to do new things, such as shoot paintballs and arrows. Camp was promoted by doctors and social workers to campers as “a fun time.” Campers and counselors discussed how camp was “a

vacation” for campers, which was especially important given the stressful context of their illnesses.

The caregiver participant in this study explained that:

For weeks I'd hear about camp and the things he and his cabin mates did. He's always loved his counselors and the things they've done were very age appropriate. The talent show, snow ball fights in July and no parents. It couldn't be any better than if they'd each won the lottery.

Breshawn described how she became interested in playing softball while at camp even though she had never played sports before; she took her new interest back home and became an active member of her school's softball team. Nelson also described how he felt encouraged to progress in martial arts after receiving so much positive feedback from the camp community; his identity as a martial artist was highly supported by people from camp.

For campers who had mobility impairments, camp activities were also accessible, which made participation easier, and it was not a big deal to accommodate them. Counselors further reflected on how camp was an accessible and recreational opportunity for campers:

This is a really great opportunity for a lot of people who normally would not be able to be in this situation for whatever reason, whether it's because they couldn't afford it or they don't have the means to get to places like this or through sheer disability. I'm really glad there's a place like Camp For All and a

program like Camp Hope that meets this need for children to be children.

(“Fred”)

However, not all experiences were seen as fun by all campers. For example, the camp director shared with me a story about such an experience. One male camper was physically larger than most other campers. During the night zip line activity, CFA staff failed to bring him a harness that would fit, even though they likely had larger harnesses in their supply area. This camper did not want to make a fuss once it became apparent he could not fit into the available harnesses, and he did not participate in this activity. Other campers and staff mentioned that activities would not be considered fun if they were not age appropriate; older campers felt they were “too cool” to do some activities they deemed juvenile, or to do the same activities as they always have done. This seemed to be more of an issue in 2007 than 2008.

### **Camp Is Something That Is Anticipated and Reflected on All Year**

The opportunities for reprieve and recreation were reflected on and looked forward to when campers were not at camp, as most campers discussed in detail. One day I overheard a camper tell another camper “This is the most fun I have all year.” The activities of anticipation and reflection were supported through camp mementos such as the memory book, diplomas and certificates, awards, and gifts from counselors.

Breshawn described the types of memories she had of camp:

Fun memories. I have a whole bunch of memories from my friends, and met new people, the yearbook that we get with all those pictures. My experience on the

zip line, the cabin I was in, the first fish I caught ever - my first fish was here.

The first time I rode a horse. The first time I'd ever been close to a deer.

In my field notes, I commented that "People are in flow here, with relaxing fun. Not talking much about outside world. Exceptions include some short stories about family or friends, but these are connected with the immediate and present activity only. No one is homesick."

### **There Is a Sense of Freedom at Camp**

This category was mentioned by almost all campers, especially those from UniversalTeens. At camp, campers were free from the responsibility to disclose their status to others, as well as the need to keep a secret from others. Additionally, they were free from responsibilities associated with school, work, and caring for siblings. As Fred explained, camp is

A place where they can feel safe and know that 'these people are here take care of me, I can have all this fun, I can basically get away with things, [be] a real cut up.' It's all in the spirit of good fun.

This category was especially mentioned in the context of how campers felt when they returned home from camp. For example, Cece explained:

I feel like I wish I could go back. I just wish I could come back every weekend! With all my friends. I just wish it was like this every day. But I know it can't be because, it just can't. When you are here you're happy all the time and there's no drama and you don't have to worry about school, worry about getting your grades. You just relax in a chill area.

Campers reported feeling relief from the stress of both having to hide their HIV status at home, as well as their chaotic and often dangerous home environments. While this category was similar to not feeling isolated as discussed in the previous section, campers also discussed that this feeling of similarity and lack of isolation as something that was relaxing for them, a reprieve from the stresses associated with the stigma of HIV. Rachel explained that “You don’t have to worry about no one saying anything bad to you, behind your back, ‘cause we’re all close and everything.” Without worry, campers were able to free to fully engage in the camp’s recreational activities.

Jeff summarized how campers viewed camp as being free from responsibilities of disclosure and other life issues:

The overall thing is that they have fun, and give ‘em some space to not have to deal with everything else that’s going on for them. It’s pretty incredible to see that. We laugh about some of the problems we have at camp because as they’ve gotten older - teenagers with hormones. But the truth is they do, they come to camp and what would be considered more ‘normal’ environment where they don’t have to worry about it and they don’t have the issues of disclosure and everything else. So they’re all in there together.

This feeling of reprieve from responsibilities allowed for a more open space in which to enjoy recreational activities with people who understood and cared for them, and this also related to campers feeling a sense of belonging.

### *Increasing Attitudes, Skills, and Knowledge*

Another major outcome reported by participants was that while at camp, they increased their attitudes, skills, and knowledge in several categories. These categories included the development of attitudes, skills, and knowledge related to anger and conflict management, confidence, disclosure, hopefulness, learning and education, medication adherence, personal growth, and other outcomes. These specific outcomes were developed within the context of the more general outcomes associated with camp participation, as discussed above. Increasing in specific developmental outcomes became a separate theme because they were viewed by campers and staff as personal *changes* that occurred within campers as a result of camp participation.

### **Anger and Conflict Management**

A specific life skill mentioned by many campers as an outcome of camp participation was the ability to manage their anger and to resolve conflicts with others. This outcome was particularly salient because social workers shared that many campers had anger management issues at home, either due to trauma, mental illness, or lack of role models to demonstrate more effective ways to resolve problems. At camp, youth were exposed to people and situations that helped them deal with anger and conflict in productive ways. The atmosphere at camp was more peaceful than that usually found in campers' home environments where it was a valuable survival skill to be seen as tough and combative. Additionally, camp staff expected and planned for anger management problems to arise at camp due to these issues. Campers and counselors mentioned improvements over time in levels of self-control, gained by thinking through problems



with counselors' help. Camp provided resources for alternative attitudes toward dealing with problems.

Bobby discussed how camp helped him: "When I used to get angry, I just handle matters myself - I'd get in trouble. Here I don't get in trouble - they just talk to me for a while...about like, how it's not worth it." However, not all interactions with counselors were peaceful. Janelle described her angry interactions with a counselor:

When I have an attitude, I shut down. I talk to one of my friends. I shut down and won't talk to that person. To tell the truth I said there's a counselor [Celia] that made me mad. Yesterday, this morning she made me mad and I...didn't talk to her, the only time I talk to her was when she said you gonna interview me just now. She just said I had to go talk to you in this same place. I just shut down and don't talk, or I just talk to somebody who won't tell her. Like I talked to one of the [other] counselors about it, and I said I wished that things changed. I don't think she [Celia] would.

I spoke with Celia about the situation between her and Janelle before I interviewed Janelle. Celia explained that Janelle fought and resisted her because Janelle "was trying to control her situation." But at the end of the day, she would say she did not really mean it. "The girl's heart just comes out in this environment," whereas it would not be welcomed or accepted at home. At camp, campers were encouraged to try to work things out with those they had trouble with, and were reassured by counselors that they cared for them.

Several counselors provided examples of how campers had improved their conflict management skills over the years. Campers who created trouble at camp were divided into “reactors” and “instigators.” Reactors were those who responded to the verbal teasing and aggression inappropriately. Instigators were those who started problems. One instigator was sent home from camp, whereas a reactor was not, even though it appeared to me that the levels of their aggression and inspiration of fear in other campers were about the same. When I inquired why, I was told by the camp director that the instigator had no interest in getting along with others; he knew he had only 4-6 months left to live, and wanted to leave his mark on the camp by going out with a bang. On the other hand, the reactor had shown some improvements in her self-control and communication during conflict situations.

### **Confidence**

Related to building conflict resolution and adult life skills was the development of confidence. Confidence during camp was demonstrated through participation in the high ropes activity and meeting new people. Confidence at home was related to discussing HIV status with people (mostly for UniversalTeens participants). One camper explained that

I think it gives us all a little bit more confidence with our lives...Go out and be you. Confidence to go out and be you, pretty much. Don't be afraid to just jump out there. Look before you leap, at the ground, but have your voice. They make sure we know you do have a voice that can be heard (Alison)

Many campers discussed how exciting the high ropes course (especially the zip line) was to them. “Monica” (UT) shared her experience:

Monica: Because on the zip line, it was just, you were jumping off or letting go on that ledge, and it was kinda like a thrill or something like that. You usually don’t get to do something like that like at home or anything like that.

Me: Did you learn anything about yourself when you were doing the zip line?

Monica: Well like at first, I was really really scared, and everyone was like “oh, it’s fun” and I was like “Ahhhh!” But finally I did it, and I thought it was fun you know, ‘cause it’s like flying through the air.

Monica later discussed that she used memories of her zip line experience to overcome other challenges in her life. Counselors also discussed how the high ropes course and other activities at camp were instrumental in developing confidence in campers:

Some of these things, like the zip lines and the high ropes, they challenge these kids to really face fears in a lot of ways. Everything from trying to climb that huge wall and to swim in the deep end or to ride horses, all these things that children maybe were initially scared of and they’re overcoming them when they have the support of counselors and campers alike. Maybe later on in their life when they’re deal with either something to do with their illness or any other thing, they may be able to look upon these situations and realize that they have the power to overcome adversities (Fred).

Camp gave campers confidence to talk to others about HIV. Alison discussed her interactions with her friends at home:

I totally be like, “what you doing? This unsafe sex stuff? It is *beyond* me! What are you *thinking*? It’s really beyond me.” Like I try to um, not necessarily educate them in a way, I don’t wanna come in and try to lecture, I wanna give back, also.

A few campers discussed how they used their HIV status as an opportunity to educate others about it and to clear up misconceptions: “I be talkin’ and tell somebody ‘I’m HIV positive.’ ‘Oh dude, that sucks!’ ‘Actually no it doesn’t.’ ‘Why you say that?’ ‘Because it keeps me busy!’” (Matt). A few of the UniversalTeens participants discussed how over time, camp changed their approaches to being confident about talking to others about HIV. These campers held the view that if someone reacted negatively to their disclosure, they didn’t want to be friends with them anyway. Additionally, they wanted to use their experiences with HIV to help and educate others.

## **Disclosure**

Issues around disclosure of HIV status to other people were frequently mentioned, especially by campers. Counselors seemed less aware that this was a major issue in campers’ lives. Confidence to disclose seemed to be a function of age: the older campers were, the more likely they were to disclose. Their willingness to disclose also seemed based on the amount of time spent at camp (particularly Teen Talk). In addition, the more that they participated in camp, the more likely they were to disclose, and to not see HIV as stigmatizing or something of which to be ashamed. Disclosure also seemed to be influenced by greater exposure to older people who freely shared information about

their status whose stories about disclosure issues inspired campers to disclose themselves.

There was a range of other people's reactions to disclosure reported by campers, from completely others dropping them as friends or acquaintances, to requesting more information and how best to support them. Rachel discussed how one side of her family ignored her and her other immediate family members who had HIV, but the other side wanted to hang out and get to know her more. There was constant tension in her household, however; her seventeen year old brother (with whom she lived) did not know the status of his family members:

If he knows, he'll like just flip out, it'd just be the grossest thing in the world.

Like if he kisses me on the cheek he's gonna get it and stuff like that, and I'm just like, that's really stupid. So we [Mom and sister] have to keep ours [medications] in the bathroom, in the drawers, or at least in the hall closets - put up on the highest shelves so he can't reach because he's so short.

Rachel went on to discuss her level of disclosure with her friends:

Yeah, some of them know. Not all my friends because I don't trust most of my friends. Like I trust them to a limit, but like one of my friends does have HIV and she told one girl and that girl told the whole school. It got to the point, where I was like, [with certainty] no I'm not going to tell her.

Later she described how a member of her sports team left the team after he and his mother learned of her status; she seemed nonplussed about it.

Campers also used the process of disclosure to rectify common misperceptions about HIV. Nelson explained how he wanted to be a nurse because of his positive experiences with nurses at camp and in his health care clinic:

I want to teach people about HIV and show them ‘hey, I have HIV. You can’t get it if I touch you, if I poke you, if I say hi to you - you’re not gonna get it - you don’t have to be *scared* of me. Just if I bleed, we have sex (which I doubt it ‘cause you’re my *friend*), that’s the only reason you have to worry about it.

Still, other campers refused to tell people their status for fear of being picked on or mocked. Disclosure issues were a source of constant grappling for campers.

### **Learning and Education**

While campers wrestled with issues about disclosure, they also gained technical knowledge of HIV through camp. This education included information about the HIV virus, taking and remembering to take medications, problem solving (such as how to disclose to others), and dating and relationships. Additionally, the informal context of camp allowed for a different method of transmission of information from that which was usually done in a medical or therapeutic setting. Campers were able to ask questions of people who had been through what they were going through, and do so in a non-judgmental atmosphere.

Campers often mentioned that one of the things they liked most about camp was the education they received:

The activities that we do at camp such as like, we had the, um, sex activity - that was more, like to me more inspiring ‘cause it taught me a lot about health issues

that I really didn't know. and it made me look towards, not actually HAVING sex, but having more SAFE attitudes toward having sex (Sean)

Importantly, several campers discussed how the educational methods at camp were superior to those at home. Alison explained the differences:

Alison: I think camp is a little bit more *in-depth*. Versus school, they don't really get down to the nitty gritty like they be doin' this week. They really *down*. They don't wanna tell you what you want to hear, they tell you what you need to know. Whereas at school, they'll tell you the basics, they'll sure tell you that sex-is-wrong. You'll get AIDS, you better watch it [hmp]. Here it's raw.

Me: Do you like the raw?

Alison: I do. It makes us more aware, more alert. Like if a guy... would just stand there and tell us that "these are the facts" and bring up a slide show and say "23.9 million people get infected every year...de de de de de de de de de." Versus the speakers that we had, they be gettin' all up, they tellin' us *all* their bizness.

Me: What do you like about the speakers that we've had here?

Alison: They very straightforward. They not afraid to...they know that we're not children anymore. We're almost at the age to have children right now. They want to make sure we understand, that we know.

Campers welcomed the opportunity to learn new things about HIV and ways to conduct their lives, and to reinforce information that they already knew. Several campers discussed how they would explain to other HIV positive youth thinking about going to

camp how much they would learn there. Others discussed how the education they received at camp encouraged them to seek out opportunities to teach others about HIV.

### **Medication Adherence**

Besides disclosure, another HIV-specific outcome was that participants reported increasing their adherence to medication regimens. Campers' responses to questions about medication adherence were fairly consistent, indicating a shared belief system and common experiences. At camp, everyone took medications (meds) so it was easier to remember to take them on time; at home campers usually needed to be secretive or were busier with responsibilities so it was easier to forget. Since everyone at camp took meds, they learned and shared techniques for swallowing pills that were often quite large, bad-tasting, and nauseating, and also for remembering to take them. This outcome also became integrated into regular health care procedures at home through doctors reinforcing the importance of, and techniques for med adherence in the clinics. Campers gained information and coping techniques about HIV meds that related to the importance of taking them, side effects, reactions with other meds, and more. Additionally, medication adherence learned at camp changed campers' clinical relationships with their doctors. At home, doctors were able to reference information learned at camp to reinforce adherence.

Cece described how she copes with taking meds at home as compared to camp:

'Cause at camp, you just have more fun. It's like people around you that's taking their medicine, like you don't have hide. But when you're taking medicine around your regular friends, it's not like you have anything to hide from them,



but you just don't feel like the aggravating questions - "oh, what is that that you're taking? Oh, why are you taking medicine?" "Oh, because..." Sometimes I tell them I'm crazy, that I take crazy medicine [laughs] 'cause I just don't feel like explaining to them why I have to do it. Because even if I do tell them, they'll just go to the conclusion that I'm loose and I've had sex, and you know, I just don't feel like that aggravation.

Another camper in my cabin began having a difficult time with her health about half-way through the week. She began feeling lightheaded, which is a common occurrence when medications begin to be taken more regularly. Additionally, this was her last chance at a medication regimen; she had failed to adhere to previous regimens which caused her immune system to become resistant to the meds. If she did not adhere to the present regimen, she would be taken off meds altogether because it is better in the long run to not take any meds than to incorrectly take them. This realization was compounded at camp, for she saw many of her friends taking meds, and recognized the implications of her failure to adhere. After talking with another counselor and social worker, she shared that it was difficult for her to adhere because her younger siblings don't take meds. This camper was the only one in her family who did, and the responsibility to maintain optimal health care at age 15 was just too much for her. Counselors, social workers, and doctors worked with her for the rest of the week; their primary message was that she needed to keep holding out and taking meds until the day a better regimen or even a cure would become available.

Sean described the difficulties he has with taking meds:

Sean: You don't wanna take medicine, you just want to be like everybody else, like regular. But then there's the scary times when the doctor brings you in and like "why not take this medicine? And this and that," or "why not take you off?" And when they say stuff like that you know you *need* it 'cause it just scares you.

Me: To be taken off?

Sean: Yeah. It's...like playing around with your life - you just want to be relaxed and fit in, so it's like that. That's why it's so confusing - it's like you want to do the right thing and take your medicine, but it has side effects on the way it make you feel and all that. And sometime you don't [take the meds] and you just feel so much better. But I don't understand and that's why it's so confusing.

Camp provided a safe space for campers to talk about such difficulties, and provided opportunities to share helpful information and encouragement.

Ashante shared her reasons for adhering to her medication regimen:

Ashante: It's helped me. It helped me with my meds. Actually I'm on more medications 'cause I didn't like medicine, I didn't want to take none of it. But then I'd be seeing my friends not take their medicine, and I didn't want my friends to die fast, so...

Me: What would happen if they didn't take their medicine?

Ashante: One of my friends, she wouldn't take her medicine at camp neither, it would look like she taking it, but she'd go in the restroom and I'd follow her in the bathroom: "Girl! Go sit down and take your medicine!" She be like "whatchoo watchin' me for?" Because I wasn't taking my medicine when I was

little, I used to put them everywhere. But then when I realized the serious thing of it. Like right now, my viral load is undetectable. So I'm good.

Adhering to a medication regimen is an indicator of caring for oneself, and of hope for the future.

### **Hopefulness**

Campers expressed hope for the future. For example, many campers explained how camp inspired them to continue to take meds to maintain good health and to prove that they could achieve in life. Hopefulness was also represented by all campers' desires to be CITs as a way to stay connected to the positive influences of camp. Karen, a social worker, explained that "I see improvements in their attitude towards their disease and coping with their future." While the aforementioned outcomes were more proximal outcomes, 'hopefulness' appeared to also be a distal outcome.

Ashante discussed giving back to the camp community:

I want to see the other little children grow up and see them be grown up and see how it would feel to be me and my age when I was at camp and help them have the same experiences *I* had. And let them have a good time, and let 'em have fun like we did when we was live [slang term for being very excited and in the moment]!

Ashante also shared more about how her attitude about medication adherence was indicative of the hope she had for her life:

Ashante: Like um, actually I had a liver transplant and my viral load went down. When I restarted taking it again, my viral load has not gone back up.

Me: You must take good care of yourself.

Ashante: Yeah, I do now. I take real good care of myself now. I didn't when I was little because I didn't care no more. My mama passed, my daddy was incarcerated, and I didn't care, I really didn't care about nothing. But now I'm like, I went to camp, and I see my friends and their experience, and I don't want them to be saying "Girl, look what happened to Ashante. She passed away." Uh, *no*. That's not how I want them to remember me - that she passed away because she didn't take her medicine. Or she did something to herself to make her pass away, or something like that.

Jeff also expressed how camp might provide opportunities for the development of hope in campers:

And it's just providing the basic information, it's pretty amazing because a lot of these kids (even with perinatal infection) like know their status, some of them may not know it very long. To a lot of them they don't understand TOTALLY, and they really have this vision of what their life is going to be because of this [having HIV] that's not true.... We've gotten questions about kissing and they're terrified of kissing somebody because they'll spread it, or all the stuff, so just that basic information really helps - they can realize I'm not some pariah or leper that has to leave, and I should take my meds because I CAN have a life. We try to talk about the opportunities they can have, like going to college, getting married, having kids someday, all these things that might be a little more difficult for them, but they're still there - they're not shut out because of this. So hopefully

they can get that and they're going to be more motivated to take care of themselves and not see it as a fatal death sentence. That they can't have a life, so what's the point. And in the past, I *think* it's worked [laughs].

Hopefulness was shown through campers' sharing information about future plans, and desires to stay healthy.

### **Personal Growth**

Campers also reported growing and maturing as adolescents and young adults. This was indicated by their willingness and openness to try new things, increasing ability control themselves, better understanding of others' perspectives, and development of identity. This outcome was especially mentioned by older campers and referred to as "getting out of your comfort zone." "Again, I think it [camp] takes you out of your comfort zone and puts you in another situation where you're forced to be around different people. And how do you socially interact with them, how do you watch yourself?" (Alison).

Additionally, many campers and staff reflected on the changes in campers who went from being shy to being more outgoing, either over the course of the week at camp or over the years: "My first time coming here, I used to hate being around a big bunch of people. I was shy, I didn't like meeting people... Like "back away!" But now I'm just out there and I'm goofy a little bit" (Breshawn). However, one counselor mentioned that a few of her campers did not seem to change at all during camp. She seemed to attribute this to the girls being too self-centered.

Having HIV provided many campers with a new attitude about life, which affected their decision making. HIV affects *every* decision in campers' lives, and camp provided youth with opportunities to consider decisions they might need to make in the future. For example, Matt's friends at home used drugs and alcohol, and he learned what his [low] limits were for drinking, and decided not to use drugs because they could have a negative effect on his HIV medication efficacy. During a craft activity, "Lynell" (CH) shared a decisive insight with the group sitting with her at the picnic table: "My dad was in a gang, he was a Crip. When you in that life, you die. I'm a stay outta THAT."

Camp was also a space for campers to develop their identities, especially as people living with HIV/AIDS: "Sometimes I have trouble accepting like what I have, but at camp I accept myself" ("Sulee," CH). One focus group member explained how camp changed him: "I think camp has changed me to learn to be who I am and to be nice to other people and have fun." The caregiver participant in the study explained that her son returned from being a CIT at camp "with a more mature attitude. He even apologized for all the antics over the years."

Experiences at camp also changed how some campers thought about others, and tended to make them more open-minded toward the perspectives of others. Monica explained:

I'm not as quick to judge people for whatever reason, for having something [like HIV], or being gay or lesbian, things like that. Some of my friends they kinda judge about that, so. I don't know, maybe it's 'cause they haven't met as many

people like that, so they just...tv I guess, you know, media. So it...they kinda have that stuck in their brain.

However, thinking better of others was not always the case. For example, one girl who used a wheelchair acted very selfishly toward Milton, who also used a wheelchair and was infatuated with her; at the very beginning of the week she expressed interest in dating him, but then seemed to change her mind. Even her friends told her to be nicer to him, but she callously ignored him during camp. Additionally, she would use her mobility impairment as an excuse to not participate in most activities, even though another girl who used a wheelchair in her cabin had no problems participating in the activities. Her counselor explained to me what a negative attitude toward life she had, and how she was partially successful in bringing down the mood of the cabin.

Some campers acknowledged that it could be hard to overcome negative influences in their environments. Sean discussed how camp provided him with role models who were leaders, and how it encouraged him to try to be a leader as well.

Sean: Maybe if I change my environment [at home], I think I'd be more of a leader.

Me: What would you change it to?

Sean: I'll try to change it to more knowledge and less ignorance. 'Cause it's more ignorance and less knowledge, that's why I feel like so much that I'm not doing anything; I'm just following the ignorance and not saying anything. Maybe I'll try.

Still, camp mostly provided a safe space for campers to reflect on themselves and their lives, and exposed them to alternate attitudes about life, which supported identity development and facilitated values clarification.

### **Other Outcomes**

In addition to the outcomes in skills, knowledge, and attitudes, there were some additional outcomes that were mentioned. However, these additional outcomes were mentioned by only two or three people, and were not dense enough to warrant their own categories. Still, it was important to include them here in order to explore the full range of outcomes mentioned by study participants.

Of these additional outcomes, outcomes related to self-esteem were mentioned most frequently. The camp director discussed the impact of camp on campers:

It's a huge benefit for them. And then here again, the kids' self esteem, their level of self esteem, any kid with the disease, and all kids, there's a certain level of self-esteem issues. So we're able to help them work through those issues to a certain level. It just increases their quality of life all over the place.

Some counselors discussed how camp was seen as an opportunity for youth to find dating partners:

But yeah, at least for my boys every year, that's a big draw for them, they can't wait to "let's go hang out with the girls" and find that girl they wanna hang out with at camp. It's so funny, it's such teenage drama, like '*we're dating.*' But you met yesterday! It's a week! But I think that's a big thing about camp for them (Jeff).



This was also observed in my cabin – talk of who was cute, who was dating whom, and other camp-specific dating and relationship topics dominated many of the conversations between girls. Additionally, campers in my cabin spent most of their free time teaching each other various dances. This seemed to provide them with technical knowledge of new dances, as well as practice opportunities in a safe space so that later they could show off their skills at dances and possibly attract boys. Of course, dancing was also an engaging and enjoyable experience.

Two CITs discussed the effects their experiences had on them at the end of camp. One young man shared how he learned how to be responsible for campers before taking care of his own needs. The other CIT discussed how his role was exhaustingly parent-like in dealing with so many highly active little boys, and how because of that, his CIT experience was “birth control.” Other campers expressed a desire to give back to the camp, such as by taking care of younger campers. This desire to help others was also facilitated by a new program at Camp Hope called “Camp Hope Gives Back,” in which cabins undertook a volunteer project such as passing out food at canteen or during meals. A few campers mentioned how impressed they were that there were actually people in the world who would take a week out of their lives to volunteer; it appeared that volunteering was a concept not often encountered during campers’ lives.

“Structure” was another outcome associated with camp participation. Structure seemed to come from the overall camp organization; one counselor explained “Although they wouldn’t admit it or don’t realize it, they need structure, it’s good for them.” Structure was also experienced on an individual level. For example, one girl in my cabin

had attention deficit disorder (ADD) and was constantly talked. Toward the end of the week, she approached me and asked if I would teach her to knit [I was one of two people at camp who knew how to knit; knitting was a craft taught by the other knitter on Tuesday and all girls were given needles and yarn]. I taught her the basic steps, and while she did become slightly frustrated at first, she persevered and eventually was able to do it on her own without my help [I think this was the longest she had gone without speaking all week]. Her intense focus on the activity (and subsequent smile of pride) seemed to provide her with a small structured respite from her otherwise unstructured responses to her ADD.

These additional outcomes were only mentioned by a few campers and counselors. However, their presence indicates some additional changes in attitudes, skills, and knowledge experienced at camp.

### **Process Themes**

The four outcomes associated with the camp experience were influenced by various processes within camp. “Processes” consisted of formal and informal policies and procedures, and social interactions. While there was some overlap of processes that influenced more than one outcome, there were differences in the strength and type of their influences on the outcomes. Processes are discussed in descending order of their salience of influence on outcomes. Table 4 provides an overview of how the processes relate to different outcomes.

Table 4. *Summary of Outcomes and Processes.*

<b>Outcomes</b>	<b>Processes</b>
Experiencing caring people	Long-term relationships, outside of camp support, exposure and storytelling, Teen Talk
Developing a sense of belonging	Acculturation, Teen Talk, medication taking, grieving, aging out of camp, storytelling
Feeling reprieve and experiencing recreation	Activities, planning for the needs of campers, accessibility, sense of freedom
Increasing knowledge, and skills and changing attitudes	Education through Teen Talk, non-Teen Talk education

*Processes: Experiencing Caring People*

The program processes that seemed to contribute most to the campers' experiences of caring people were long-term relationships, outside of camp support, exposure and storytelling, and Teen Talk (where campers could share feelings and experiences). "Caring" was most often evidenced by genuine attention paid to campers, hugs, high-fives, and active listening. Counselors physically interacted with campers (especially smaller ones), such as picking them up or teasing them. Additionally, all campers wore nametags with their first names on them which facilitated calling all campers by name. These interactions were especially important for this population because many people in their lives avoid contact with them due to the stigma associated with HIV/AIDS.

### **Long-Term Relationships**

Campers experienced caring people the most through long-term relationships between campers and with staff. Knowing that they would see the same (or mostly the same) people at camp year after year was reassurance that people cared about them, and provided some continuity of relationships in their lives. Campers knew that each summer they would get to engage in friendships with the same people as they did in the past, and this was an incentive for them to return. For those campers who attended Camp Hope for several years, they felt that they grew up with their camp friends. As Jeff shared, “This is my eighth year - some people have been here since the very beginning of camp. So it’s great to let them know that there’s this community of people who REALLY care about them.”

Camp Hope typically has a high percentage of returning staff – over 80 percent. In 2008, there were approximately 11 new counselors out of 60. One of the veteran counselors “Gary,” shared the primary reason he works at camp: “I come back to see the kids that I’ve come to know and work with the counselors that I’ve worked with. You just get so much out of the kids, it’s just a lot of fun.” Celia explained that she works at camp because of the warm feeling she gets when campers disembark from the bus on arrival day and want to know if they are in her cabin as they give her hugs and warm greetings.

Even though most campers had new counselors every year (counselors tended to remain with the same age group), they still saw and could interact with their former counselors during all-camp programs and meals. These long-term relationships were

highly valued in the culture of Camp Hope. For example, during staff training, the group enthusiastically clapped for and smiled at a CIT who had attended camp for over 10 years. As another example during training, a counselor's jokes filled with sexual innuendo was largely accepted by the camp director and the group; this was likely due to his elevated status as the most veteran counselor. It appeared that strong relationships between counselors were formed based on shared experiences in the years before; however there was little structure to create these relationships for the first-year counselors.

As a new counselor myself, I looked for ways to create relationships with more experienced staff and campers. I noticed that Camp Hope campers were hesitant to talk with me for the first three days of camp; by Thursday some of them began to open up more about their feelings and the problems with which they grappled. I also felt that many of the veteran counselors ignored me, even when I smiled and waved hello. I attributed this to the phenomenon of gay men preferring not to interact with women, or to my status as an outsider, a first-year counselor. I did not believe it was because they saw me as a researcher; most people were not paying attention when I introduced myself as such during staff orientation. During a member check, the camp director suggested that the other counselors' reactions might have been because some counselors prefer to interact only with counselors who work with the same ages of campers as they do. At the end of Camp Hope, however, several campers told me that they wished I would return next year. Cece wrote in my memory book:

“I loved the little talks that we had. You gave me a better outlook on life N I’ll never 4get you or the way you are. I’ll be so sad when there Is NO one around for me to talk about life and/or the future. I really enjoyed being around you and sleeping by you LOL. Keep your head up and never change. I loved you N hopfully I’ll see you Next year and we will have even more fun than what we had he. XOXO Love always, “Cece” and If you would like to keep Ntouch my email is...”

Alison explained her feelings about long-term relationships: “At camp, it allows you to interact with other people, and build relationships, and then they carry on throughout your life if you CHOOSE to do it, keep in touch with that person.” Most campers felt strong autonomy to continue relationships with other campers outside of camp. However, it was a camp policy that counselors not maintain relationships with campers outside of camp. This was because the camp wanted campers to develop deep, lasting relationships with others, and counselors were perceived as being too transitory in campers’ lives. Additionally, this policy existed because some counselors could become *too* involved in campers’ lives, or take it upon themselves to ‘rescue’ them from their negative living situations. Karen explained how out-of-camp contact might occur:

Every year there are kids that want to stay in touch with certain counselors, and occasionally it has been arranged if the psychosocial team that specifically cares for that child...psychosocial and medical representatives are at camp that know the child intimately ‘cause they’re from that clinic, if they agree that it would be a positive thing to stay in touch, especially the ones that are [*inaudible*] then they

allow it to happen, but it's always under...more has to be taken into consideration - the people that care for that child. Instead of just unmonitored, and counselors giving out numbers at will, so it's kind of those where a special relationship develops and they feel that it would really help this child to continue communication then it is allowed. The parent, caregiver, has to give consent after camp for it to be okay.

With more long-term relationships came more chances that friends would pass away. Sean remarked about his counselors that "They're like happy to like *see* you every time they come. 'Cause some kids they don't even see - some kids pass away." Another focus group participant explained that camp has changed "because a lot of people has came and gone, like passed away or whatever. But all my friends, they like gone, so a lot of our camp has really changed." Although most campers did not seem aware of this, the back of a bench outside the dining hall was affixed with metal plates with the first names of Camp Hope campers and staff members who had passed away. This was another way to acknowledge and maintain the community of caring people at camp.

### **Outside of Camp Support**

Campers experienced caring people - doctors and social workers - outside of camp as well. Members of the medical and psychosocial teams were highly involved in campers' lives, and this thread of connection made it both possible for youth to be successful at camp, and to be successful at home. The relationship worked both ways. As Karen explained:

It gives me the opportunity to see them outside of their clinic visit. It gives me the opportunity to learn about them on a more intimate level and have them see me as more than just the social worker in the clinic, they see me and they want to talk to me and it's more of a relaxed atmosphere. It provides me the unique opportunity to see them in a different light and also on the flip side to see *me* in a different light.

The medical and psychosocial teams saw camp as an additional support in their efforts to encourage campers to take care of themselves, adhere to their medication regimens, and develop successfully. The camp director explained that these people had great power in deciding who got to go to camp: "If you're adhering with your medication, if you're doing good in school, if your behaviors are not outlandish, then we'll put you on the camp list to go to camp this year." Additionally, doctors and social workers used information gained from campers during camp to help them when they returned home. For example, one social worker asked me to keep an ear out for anything that a certain camper might say about her father - she believed he was abusing her.

Doctors and social workers were also able to view campers in a non-clinical setting, and this allowed for more opportunities to observe more natural camper behavior. For example, one doctor shared with the camp director, who in turn shared with me, how a first-year camper had an anxiety attack during camp, and how her behaviors during the attack reminded the doctor of a similar incident in the clinic; that time she was able to diagnose it and prescribe medication to control it. As the camp director shared:



And that's why you see so many from the different groups [nine Texas and Florida health care centers that partner with AFH to send youth to camp] that have medical folks out here 'cause then they can do a different type of assessment on these kids than they do in the clinic. The kids are more relaxed, so the ability to share what's going on with them in their life is increased.

The doctors and social workers had in-depth knowledge of issues in campers' lives, and used this information to create a more supportive environment at camp. For example, a meeting of social workers, doctors, and camp administrators was held one week prior to camp to share individual campers' issues, such as changes in living situations, anniversaries of deaths of loved ones, who got along with whom, and changes in med regimens. Ideally, this information was to be shared with the counselors of the campers, and a comprehensive form listing this information was available. However, this information was not always effectively passed along to the counselors; the forms were filled out rather superficially (at least for my cabin), and provided little information on issues that individual campers were facing outside of camp that could have been used to make decisions. Additionally, a social worker was assigned to each cabin group for the first two and a half days; however, not all social workers knew all the campers, and information would often be shared only in passing with only one counselor of the cabin, or while adults were watching the campers engage in activities on their own. Regardless, the *most* vital information (mostly about anger issues or lack of medication adherence) seemed to be transmitted effectively, and such problems were successfully handled or avoided. The ultimate result was that the medical and psychosocial teams provided

support to campers in and outside of camp, and because of this campers experienced caring people in their lives.

### **Exposure and Storytelling**

Campers experienced caring people by being exposed to them and hearing their stories. In their often isolated home environments, many campers had few if any opportunities to interact with other HIV positive youth and adults; the people at camp demonstrated that they cared about campers through taking interest in their lives, sharing their own struggles, and providing motivation to campers to succeed. Alison explained what camp meant to her:

It's an eye opener. I mean, I wish everyone had the chance to experience something like this. No matter if it's camp, or your ailment, or your... You know camp just, it's good to just get out, get outside, get out of your comfort zone and just meet new people, get to see a different side, not just your perspective. Get to meet people from around the world.... and these people are exposing themselves and telling us their intuit...most personal feelings. I think it's good, it's awesome. I wish everybody had a chance to, you know

“Getting out of your comfort zone” was a phrase frequently used among staff and campers. Campers were exposed to different ways of thinking, attitudes, and experiences through their interactions with others. Being with similar others enabled campers to feel comfortable enough to tell their stories to a supportive and caring audience, and to get answers to their questions, which in turn served as stress relief for them. Additionally,

hearing how others solved problems in their lives provided inspiration for their own lives. Raini described these interactions:

Camp Hope is something that is a constant source of positive energy in their lives, it's something that they look forward to every year, it's something that they really enjoy while they're here and the relationships with the counselors and [the camp director] and stuff really sort of provide stability in their lives when they might not have adults in their lives at home that are really secure with them.

As the camp director explained, "We can't fix them, we can only expose them....It takes a village, but their everyday village is not supportive. But at least they now know something else, a different way." This was a major operating premise of camp. "Denise," a counselor, shared her perspective on the feelings of caring that campers take home with them to their everyday lives:

I would really hope that they do, because I don't feel like I'm doing my job if they don't. I want them to be able to know that there are people out there that really do love them and that are there for them, although we're memories during the year because we can't be there for them but I think that's the one thing they can hold on to, "I can go back there again and experience that again next year" so that gives them something to look forward to during the year. Then, hopefully, by setting good examples here we can plant a seed or give them some little piece of something they can take back with them that will grow and flourish into something.

**Teen Talk**

The camp director explained that the purpose of Teen Talk was to provide a safe space for the sharing of information about HIV and AIDS, including the importance of medication adherence, disclosure issues, basic information about the disease, and transmission. Teen Talk sessions lasted one to two hours, and were led by counselors who were HIV educators outside of camp, and had been involved with Camp Hope for several years. No other counselors, doctors, or social workers attended; both Junior and Senior Teen Talks were each run by two facilitators with about 30-40 campers each. The relaxed and informal setting of Teen Talk provided a supportive opportunity for campers to learn or relearn information that they also learned from their social workers or health care professionals in clinical settings. Social workers and health care providers were typically seen by campers as authoritative figures. Given that social workers and health care providers had known campers their whole lives, they typically interacted with campers in commanding or parental manners. Campers received information in a relaxed and non-medical setting in which they felt comfortable to ask questions that they would otherwise have been hesitant to ask for fear of being judged by their social workers or doctors. As adolescents and young adults, they were interested in being sexually active and wanted to be responsible about it, but may have felt intimidated in going to their health care providers about their needs for birth control, condoms, techniques to reduce likelihood of transmission, and other health concerns. While they knew they needed to be responsible and compliant with their medications, they often became weary of taking meds due to life's responsibilities. Many believed that if they

shared their fears and concerns, their health care providers would become authoritarian and say “No! You HAVE to take the meds!” In Teen Talk, they had an avenue to safely discuss these issues, could network and exchange information with other youth with the same challenges, and could talk to trained people to get “raw” answers to their questions.

Nearly all campers discussed how important Teen Talk was to helping them experience caring people. Ashante discussed the interactions that happen during Teen Talk:

We get our expression out, and it be real deep, it real deep at Teen Talk, and so we get our feelings out, and people get real emotional at Teen Talk, but like you get out and it calms us down. It really helps us....You hear other people’s stories about their status and stuff like that, and what they goin’ through, and hear from different people and stuff like that.

Carl shared that Teen Talk “was the place to go to go talk with other people and get their opinions and share yours too without any judgment or anything like that.” Devin also explained:

Like we get to experience things that we won’t experience at home. Like you can’t just expect your parents to sit down and talk to you about things you’re gonna have to do in life....They take us to Teen Talk, they take us to a quiet place. They don’t force you, they let you get your feelings out. When one person does, you *all* just let it out.

Dr. Helen explained what happens in Teen Talk:

Helping each other with the medication issues. A lot of them can be on similar meds and so one may have struggles and the other one will counsel them and say “You know this is something that’s saving your life. You know you’ve just got to do it.” It’s the peer counseling that really replaces or does a better job than anything I can do.

Additionally, campers were encouraged to ask questions of the facilitators during the day, and during Teen Talk they were given cards on which to ask anonymous questions to be answered on the last night of Teen Talk.

Emotions tended to run high during Teen Talk; this was one of the few (if any) places that campers had a caring group with whom to discuss their feelings. In Teen Talk, they interacted with campers and staff who cared about their health and well-being, and who wanted to help them overcome difficulties and achieve their goals.

### *Processes: Developing a Sense of Belonging*

The program processes that seemed to contribute most to the campers’ development of a sense of belonging were acculturation into Camp Hope, Teen Talk, medication taking, grieving, aging out, and storytelling. While these were specific processes within camp, the overall existence of camp also contributed to campers feeling a sense of belonging to a community bigger than themselves.

### **Acculturation into Camp Hope**

This process category was the densest of all categories. Like all camps, Camp Hope had a particular culture consisting of various group norms. Campers’ acknowledgement of and adherence to these norms was evidenced throughout interviews

and observations. Being a part of the Camp Hope culture provided campers with a sense of belonging to something bigger than themselves. There were three parts to this acculturation: common ground, group bonding, and social controls.

This sense of belonging came from a shared (if not always spoken of) *common ground*. Knowing that everyone at camp had the same status was reassuring to campers, and was the foundation for why camp was so memorable in their lives. For example, Carl explained why camp was special to him:

Carl: Basically how things are run around there. And like the way you're treated, the way people talk to you, the way you do things around there. That kind of environment.

Me: What's the way?

Carl: Kinda like, you're just an ordinary person there. You're just one of the few people in the crowd.

Matt discussed the value of this: "But at camp, there's just one common ground that connects everyone. So it's a lot easier to make friendships, it's a lot easier to get to know people. To have a more understanding shoulder to lean on."

However, this common ground of shared status was unspoken during all camp activities except for Teen Talk; campers 11 and younger did not necessarily know their status because their caregivers had not chosen to enter into that conversation with them yet due to their fear of potentially negative effects of stigma on their children, or because disclosing their own status would give away the method by which they were infected (typically via drugs or sex). The words HIV and AIDS were never spoken during camp,

and staff members were trained to refrain from saying them or wearing clothing that referenced them, such as AIDS Walk t-shirts. It was not difficult to refrain from speaking these words given the cloak of secrecy campers experienced in their everyday lives. Typically, older campers and staff danced around the words by saying “have what you have” or “what you’re going through;” this was also highly evident within interviews, especially at Camp Hope.

During down time in my cabin one day, I overheard a camper approach another counselor and ask “Does everyone here know they have HI...?” The counselor explained that everyone 12 and older knows, but the camper shared that a boy in the next cabin might not know his status due to his developmental delays and forgetfulness, and his trouble understanding English (he spoke Spanish, like our camper). The counselor reinforced to the camper that it was not our place to tell him his status. After a pause, the conversation turned to what to do about sharing personal contact information. The counselor explained that they would need to pass this information through their social workers because of confidentiality. The camper looked confused, so the counselor gave an example:

If I see you in a restaurant where I’m eating and you’re working there, and I know you, and my friend asks me how I know you, I could say it’s from Camp Hope. But if they ask what Camp Hope is, that would be telling your business.

Another camper jumped into the conversation: “Well, I would just say I go to Camp Hope because I need hope!” While older campers knew that the campers at camp were



HIV positive, this was treated as a communally shared secret, and only discussed within Teen Talk.

Acculturation also occurred through *group bonding*. Several spontaneous instances of bonding occurred during unstructured free time that led to greater group cohesion through shared experience. The groups that bonded together were typically groups within the same cabin, or the entire cabin; there were few between-cabin groups. For example, in my cabin one night after Teen Talk, it was discovered that boys from the next cabin wrote some (relatively innocent) graffiti in chalk on the walkway outside our cabin. The girls decided that this was grounds for retaliation, and devised a plan to distract the boys while other girls wrote their response in chalk on their walkway. The other counselor in my cabin supported this idea, and helped them to hone their plan of retaliation (unsure of the appropriateness of this, I hung back). After losing their nerve several times and shrieking when the boys saw them sneaking around their cabin, the girls devised another plan, practicing some self-control and patience while things calmed down at the boys cabin. However, their second attack also resulted in screams and shrieks. This woke up girls in the next cabin over, whose counselors were quite upset that our girls had undone all the work they had done to get them to quiet down and go to sleep. While this was an unfortunate side effect, our cabin really bonded as a group; one said “This was the most fun yet this week!” Everyone had been involved in working together as a team on different, necessary tasks and roles to accomplish the mission. Even though this late night activity was unscheduled and unproductive, it was the moment that our cabin finally gelled.

The cabin group also bonded as they worked as a team to prepare for the talent show; their goal was to have one camper sing while the rest danced. They bonded through teaching each other the dance moves, being supportive and encouraging, persisting through frustration, negotiating leadership roles and ideas, listening to each other, and being honest. Belonging to such supportive friendship groups at camp was also seen as being preferable to those at home. Matt explained the difference: “And then I come back home and I see what MY friends are doing, or what I consider my friends. And I’m just like, ‘Can I just stay at camp a little more longer?’” Some campers explained that these bonds also formed through shared, funny experiences such as skits and jokes created by counselors that were amusing to campers.

The culture of camp was also defined through various *social controls* that were accepted by most campers. Those campers who deviated from the norms were disruptive, would not share their feelings, or would not participate in activities. These campers were roundly ignored. Occasionally, the non-conforming campers would be talked to by other campers, but generally, campers did not want to get into arguments or disagreements, so they chose to ignore negative behaviors. Occasionally, campers would forthrightly address negative behaviors and attitudes; when this was done, it was meant as a sign of respect. Most campers did not have people in their lives would try to help, support, or work through examining the reasons why they had a particular attitude.

The group norm for both programs was to be open to new experiences and people, and to soak up the overall program experience. This openness seemed predicated on the preexisting relationships campers had with other campers and staff; there was

already a level of trust that what they were being exposed to would be good for them. At camp, the behavior that got positive attention was sharing a profound insight or experience, or seeing something in a new way; this type of behavior was rewarded at camp with social approval.

A more formal method of communicating the expectations of the camp culture was through the “Camp News Network,” a Power Point presentation delivered each morning by CFA staff that highlighted different campers’ accomplishments from the previous day. Examples of accomplishments included cleaning cabins, helping others when they were homesick or taking meds, cleaning tables, earnestly participating in activities, teaching others, and remembering to take meds. The Camp News Network was another method of positive reinforcement and sharing expectations of appropriate camp behavior. As Raini explained:

I think they realize that they don’t have to be tough or this sort of personality that they’ve learned to be back home. There’s nothing to hide from out here, they can just sort of open up and nothing is going to happen to them, like they’re not going to be made fun of, they’re not going to be ridiculed or whatever. They feel safe here and so once they realize that this is an area where they can feel safe and that we’re trying to help them feel at home here then that is really what helps them out.

Interestingly, there were some differences in perceptions by counselors about what were and were not “appropriate” interactions between girls and boys; this emerged in the post-camp staff evaluations of the program. Some counselors seemed to feel that

certain behaviors were okay for campers, such as holding hands or showing affection. Others were appalled by the campers dancing provocatively with each other to sexually suggestive songs. Additionally, another cabin reported frequent occasions of disrespect for counselors, and held “positive talks” about it throughout the week to try to guide the group’s behavior.

While there was general consensus on behavior, it seemed that there were between-cabin and between-counselor differences on what was acceptable. For campers who had changed counselors that summer, these differences may have contributed to some behavior issues because campers were unclear about the expectations of their present cabin culture. Generally, however, through acculturation into the group norms of Camp Hope, campers felt a sense of belonging to a positive group that was supportive of their needs and cared about them as individuals.

### **Teen Talk**

Teen Talk was another forum in which campers felt a sense of belonging, for they were able to discuss matters related to HIV in this setting. As discussed earlier, one of the purposes of Teen Talk was to create a safe space for campers to share information and issues related to their diagnosis. There were specific boundaries placed on this sharing: 1-2 hours each for three nights with groups divided by ages, and facilitated by two HIV educators. Outside of these boundaries, campers did not discuss HIV. Jeff explained:

I think in general everyone deals with the issue of HIV very well here. I like the idea that even though, some of the younger kids don’t understand, it’s not talked

about, it's not made a big deal. We do Teen Talk at night and so of course that comes up, that's what's focused on for the most part. It's just a chance to NOT to have to think about it.

The setting of Teen Talk facilitated these outcomes. During a member check, a Teen Talk facilitator described the setting in more detail. The Teen Talk setting consisted of it being held at night, in particular locations, with different group arrangements, and with skilled facilitators. Conducting Teen Talk at night provided participants with a sense of mystery, quiet, and intimacy after a long active day. Younger campers also were in bed by the time Teen Talk was held, and older campers were less concerned about having the younger ones overhear them discuss HIV, and about needing to ensure that the younger ones were taken care of. Several locations around camp were used to conduct Teen Talk, and all had different pros and cons. The best locations allowed for individuals in the group to be able to hang back and observe if they wished; it was important for campers to be able to hide their emotions within the larger group if they needed to. Holding Teen Talk in these locations was also more effective if the lighting was low or dim. Good locations for Teen Talk included holding it in locations that felt "contained" so that campers were not tempted to leave the group; the use of pillows on the floor helped encourage the campers to stay focused on the present activity, and not be tempted by other interesting things nearby.

Teen Talk was predictable; ground rules would be discussed, information would be shared, and campers would receive candy afterwards. These expectations were passed along from older to younger campers through the years so that preteens looked forward

to finally getting the opportunity to go to Teen Talk themselves. Finally, the facilitators role modeled behavior expectations throughout their presentations of the material. For example, the two facilitators would momentarily allow themselves to get sidetracked with a funny joke, but would quickly and transparently bring the group back to its focus. Facilitators were seen as people who were approachable; if an individual felt uncomfortable asking a question in a large group of Teen Talk, they would take the facilitators aside during the day to ask their questions.

The group norms and supportive culture established in Teen Talk seemed to spill over into other social interactions throughout camp; while the *content* of Teen Talk was confined to that context, the *social and behavioral expectations* carried over into other camp contexts. During Teen Talk, campers could freely discuss issues they have with medication adherence, disclosure, and other HIV-specific topics, and hear from others who are facing similar situations. This opportunity provided them with a sense that they were not alone, and that there were others like them. Additionally, many campers did not have access to such a safe place to talk about HIV outside of camp; discussing HIV at camp was seen as a particularly valuable opportunity in campers' lives.

### **Medication Taking**

Another camp process that contributed to campers feeling a sense of belonging was the procedure of taking medications. Medications were distributed twice a day by the medical team to a designated counselor in each cabin. After meals (usually breakfast and dinner), counselors gave each camper their Ziploc bag of medications. There were some anomalies of medication times; for example, some campers had to take an anti-

nausea pill 30 minutes before another pill, some meds needed to be injected, and some meds needed to be taken during non-meal times. Jeff explained how medication-taking was handled:

Me: When you say that you deal well with the HIV thing here, what do you mean?

Jeff: I think it normalizes it for them, so that I mean, I can just imagine what it would be like. But I think it's the biggest deal, it normalizes it so it's not like "Oh my god, it's this big deal." Like the med delivery is handled very - everything's sort of handled in a sort of way that's not - casual's not the word, that makes it sound [laughs] - I don't know the word for it, I wouldn't say discreetly, it's just matter of factly, not made a big deal out of, not stressed, it's just a part of the routine, it's no big deal. And so it's not like being called out, it's not calling attention to them. A lot of the kids have health issues outside of HIV but like in my cabin this year we've got some serious health issues [laughs]. Just everyone's very sensitive to it, but at the same time, not so sensitive about it, like putting up barriers around it and tiptoe and make sure it's just a fact of life, let's move on.

So I think it does play a big part, and the kids are like "Ok, we'll just take them."

At home, campers may have been the only ones in their households taking meds. At camp, they saw most other campers taking them as well, which seemed to highlight to them that they were not alone. Nelson shared:

Like when I'm at home, I forget that I have HIV, except for those 3 seconds when I take my medicine, I forget. But when I'm at camp, it's always on my

mind “Oh yeah, I have HIV. This person has HIV, that person has HIV.” I’m surrounded by people that are like me, so it’s like I’m not alone, so to speak. Additionally, campers were able to share information about how to cope with side effects of different medications. Sometimes it seemed that typical demographic differences such as ethnicity or socioeconomic status made less difference to campers than did the type of medication they were taking; those with the same regimen had the most opportunities to bond.

### **Grieving**

An issue continually faced by most campers was grieving for friends and relatives who had passed away, often due to AIDS. Camp provided an opportunity to deal with feelings that arose from grieving in a supportive and nurturing manner, especially since so many campers faced similar losses. The deaths of mothers and camp friends were discussed during Teen Talk and unstructured time in the cabins. Many campers commemorated the anniversary of a loved one’s passing while at camp, and were treated by others with respect and care in their grieving; grieving was not ignored.

In my cabin, one girl commemorated the anniversary of her mother’s passing, which was partially due to her mother not taking her HIV medications. Additionally, the girl was still upset that her grandmother failed to give her a proper funeral. Often, she was unengaged in the activity, and would put her face down, cross her arms, pout, and refuse to talk. The Lead Counselor took her to talk to her social worker who helped her process her feelings. She returned to the group feeling better, and was able to participate more fully in interactions with others and activities.



One reason that this issue was brought up for this camper was a discussion held the first night of camp during Teen Talk. A popular camper (“Edward”) had passed away the previous winter, and his loss was deeply felt by many at camp. Although accounts varied, it appeared that he passed away because after his mother died, there was no one around to encourage him to take his meds, and he lost hope for his life. Additionally, he had a major meltdown at camp the summer before and appeared to wish to take his life at camp because that was the only place he had in his life where people loved him. Whenever Edward’s name was mentioned, the people who knew him would sigh and look down. Then the mood of the group would shift to a heavier one of grieving. I observed this phenomenon of Edward in several different domains: UniversalTeens, talking with the camp director, during staff training, in a meeting with doctors and social workers, and from another counselor when we were chatting alone in our cabin.

Additionally, the parent participant in this study mentioned Edward’s passing as one of the important life interactions for her son; he was there to support Edward’s brother and mother after the funeral. During the pre-camp meeting, the doctors and social workers decided that they needed to address Edward’s passing on the first night of Teen Talk. Many campers were close friends with Edward, and not all knew of his passing; doctors and social workers attempted to talk prior to camp to those campers who were closest to him. In a way, Edward and other campers who have passed became a part of Camp Hope’s institutional memory through stories told about them and what they went through: the mere mention of their names highlighted the connections campers

have with others with HIV, reinforced the caring of their HIV community, and served as a caution to try to stay healthy.

### **Aging Out of Camp**

Related to grieving as a form of social bonding that promoted a sense of belonging was the crisis faced by 15 year old campers who aged out of camp. Realizing that it was their last year to be with people at camp, most of these campers (20-30 each summer) faced issues around closure and transitioning, and it was particularly difficult for them since they faced similar changes outside of camp such as shifting family structures, friendships, etc. Breshawn explained how she felt about aging out of camp:

Saaaad. I'm gonna miss it. I got a lot of memories here. Like they don't even have to do nothin', you just look at a place and then remember what happened. Like when we first got here, I looked and saw this building [dining hall] and saw all those crazy dances they had us doin'. And how karaoke, how everyone was embarrassed to do it. And on the high ropes - my experience going down and my friends like "it's nothing, it's just a good experience." And I was going down like "YOU LIED TO ME!" I was crying, I ain't never experienced anything like that.

At the end of the week, campers' emotions about aging out of camp reached a fever pitch. Breshawn shouted "*We grew up here!* It's not fair we have to leave just 'cause we're 16!" She and another camper discussed how they "live for camp" and offered to donate money so they could stay another year.

In 2007, the camp began providing a graduation ceremony to attempt to bring closure for these campers. In 2008, the camp director and Senior Teen Talk facilitators

talked to the campers aging out about how they had grown up at camp, provided some inspirational readings, and shared that there are next steps that they could choose to take: participate in UniversalTeens, and apply to be a counselor-in-training (CIT) for the summer after the next one (it was preferred that campers take a year off to mature before coming back as CITs). Two CITs discussed their experiences, and one of the two also talked about the UniversalTeens program of which he was a participant. Campers received a framed “diploma.” However, due to the administrative mistake that wrongly recorded many of the camper’s ages, about 15 campers did not receive their diplomas at that time; this seemed to create a fissure in the sense of belonging that these campers had with the group, which was compounded by the fact that their connections with others would imminently be dissolved.

### **Storytelling**

Although aging out of camp was the impetus for feelings of crisis, it was perceived as such because of the strong connections formed between campers who shared their stories. People at camp comprised a welcoming audience – they did not judge or act mean toward people who shared their feelings. This was different from other parts of campers’ lives in which they needed to hide their feelings, show toughness, and be brave, which was often stressful. The need for hiding appeared to decrease over time as youth gained more exposure to people who were outspoken about their status and feelings.

Storytelling in camp was an opportunity to share, to inspire others, and to be inspired. Watching the expressions on others’ faces and their nodding heads confirmed

that they understood what someone was saying, that they too had had similar experiences. Carl explained “I guess talking to other people about them and their experiences when telling somebody kind of encouraged me to finally tell somebody - lifted off my shoulder.”

Nelson, who was particularly forthcoming about his HIV status, discussed the following experience sharing stories with a fellow camper in Teen Talk:

‘Cause that’s when people like...it’s confidential, so like what we say there stays there. But it stays in your head. So like one time, I told this girl, she was like “What happens if we’re going, in science class, we’re going over HIV - do I raise my hand and answer the questions and act smart? Will they think that I have HIV, or should I just sit there and do nothing?” I was like “Raise your hand! You’re smart. Just because you’re answering all these questions about HIV doesn’t mean you have it. It means that you’re educated on it, so raise your hand.” The next day we were leaving and she wrote in my book “Thanks, I will always remember what you said to me - I’m gonna raise my hand in science class now, and be smart like you said.” That’s like one of the main things that hit me.

Passing along information through personal stories and experiences was a major method by which campers feel connected to others with a sense of belonging.

#### *Processes: Feeling Reprieve and Experiencing Recreation*

The program processes that seemed to contribute most to the campers’ experiences of reprieve and recreation were camp activities, planning for the needs of campers, accessibility, and freedom from worry. Camp policies and procedures were

fine-tuned over the years, resulting in ever-increasing efficiency and understanding of camper needs and behaviors. Experiencing a sense of reprieve and recreation (i.e. freedom from stress and freedom to engage in activities) was grounded in the caring relationships and sense of belonging campers felt in camp, and in turn served as the foundation for the development of knowledge, skills, and attitudes. The “reprieve and recreation” outcome was achieved through the processes of planning and implementing goals associated with providing a recreational experience for campers, and the activities found within camp, including Teen Talk.

### **Activities**

Participation in the fun activities available at camp helped campers feel a sense of reprieve and recreation. Camp was portrayed to campers by doctors and social workers prior to the summer as “a fun time.” As the camp director explained, “We want our kids to enjoy the experiences that a recreational camp provides.” Camp Hope worked closely with CFA to determine which activities to provide each year. While deciding what activities to offer based on what facilities, staff, and other resources CFA had available from year to year, there were Camp Hope-specific activities as well that were anticipated and enjoyed – particularly the dance (a second “blacklight” dance was added in 2008) and the Talent Show (which CFA operated after being run by Camp Hope in previous years). Campers anticipated and looked forward to these activities; they formed a repetitive tradition that created a sense of security through achievement of expectations. The camp director (CD) shared the process of how activities are planned:

CD: We changed some of the programming up. We did some specialized programming that we've never done before.

Me: Like what?

CD: Like the slumber party, which you were at. The nighttime zip for the guys. That was kind of a neat thing. We've kind of separated out a little bit more this year and started it a couple of years ago actually, where the older kids are not doing some of the same things as the younger kids. They got to the point where they're like "That's baby stuff. I don't want to do that."

Me: I remember that from the focus groups last year, like "oh, we did that, we're over it."

CD: Yeah, we needed to change things up, we need some fresh things. It's a challenge, number one, with the camp, because you think "Oh there's a whole lot of stuff (and there is) that you can do in a camp setting." And then we factor in the fact that we had such a high percentage of our kids that are returning. And then we get "Oh, we're doing the same thing." The challenge then is for CFA first, to be able to come to the camp directors and say "Ok, here's something we're starting." A couple of years ago they asked about doing paintball. At first I turned my nose up at it and then was like "Oh I'll give it a try." Now it's HUGE, the kids LOVE it!

Me: Our girls loved it so much.

CD: Ok, cool! So the challenge there, and from a camp director standpoint, my challenge is being open or receptive to this stuff. And just seeing where we go with that.

Much of the enjoyment of the camp activities was based on the activities being new to campers; campers often did not have the perception that such activities were available to them in their daily lives. Denise explained:

They're invited and, of course, a kid wants to come to camp. I mean some of these kids have never seen a swimming pool, this is just a dream for them. It's truly the ultimate vacation for them and then especially being ill, it just makes it that much better for them.

The element of uniqueness was also apparent within camp, as Devin explained why he liked the bike riding activity so much: "'Cause we got to see more of the views of the whole campus. Usually we don't get to see ALL of the campus, we just see our cabin and the pool and stuff like that." Camp activities were especially enjoyable if they had an element of danger and excitement, particularly the zip line, paintball, archery, and horses. However, the canoeing activity, while containing the elements of danger and uniqueness, often seemed to be too far outside of the campers' comfort levels due to its close proximity to nature, i.e. "dirty water."

### **Needs of Campers**

Prior to camp, plans were made to adjust the programming to accommodate the needs of campers, particularly their ages and propensity to tire easily. Dr. Helen explained how ages of campers seemed to influence their activity preferences:

Swimming, swimming, swimming - probably like their top that they all like the best. And then I think it depends on the age group, the little kids really like the fishing, the older kids may be not so much. And I think that for the older kids I think the activities tend to be less important and more about being together and seeing people and hanging out and whatever, and for the younger kids they love the horseback riding, they love the swimming, they love kind of all the different activities.

“Younger kids” ranged in age from 6-11, and “older kids” were those ages 12-16.

Regarding age appropriateness of the activities, the focus groups in 2007 contained several mentions of campers feeling they were too old for certain activities. In 2008 I did not observe any indications of this, perhaps because an unpopular activity (a diversity education reading activity) was dropped from the schedule. Additionally, efforts were made to offer different cooking, crafts projects, and evening activities for older and younger cabin groups. Throughout the week, the other counselors in my cabin and I noticed that our girls were often irritated by members of our “brother cabin” who were viewed as immature and annoying; boys teased girls, tried to draw attention to themselves, and found other ways to be disruptive. Most of the activities throughout the week were done with our brother cabin, which resulted in some fatigue due to constant proximity by the end of the week. There were a couple of opportunities for our girls to engage in activities with the older girls in our cabin group (i.e. MAC makeup, slumber party); my fellow counselors and I felt that it would be helpful to offer more opportunities for all-girls activities in the future.



During staff training, the camp director informed the group that the daily schedule of camp was adjusted that year based on the previous year's counselor requests for more rest time and sleep for the campers. Rest time after lunch was increased by an hour or so, and evening activities were cut down to end at 9:00 p.m. so that Teen Talk would be over earlier. A doctor explained that there were "fatigue issues around HIV" due to the disease and the medications, and that many campers were "couch potatoes" at home; when kids came to camp and were much more physically active than usual, they got tired. Additionally, the heat of late July in Texas was a major factor in campers' fatigue, especially during the outdoor activities. When they got tired, they got cranky and behavior problems occurred. The increased rest time seemed to be successful at decreasing (but not eliminating) this propensity, according to many staff members.

Another major change that was made from prior years was to the adult to camper supervision ratios. During staff training, the camp director explained that more counselors were assigned to each cabin because the campers were getting older, which meant more behavioral problems (especially for boys). The increased ratio was created because during the previous year there were several instances of behavior problems that stemmed from campers processing events in their lives related to HIV and family. Additionally, the camp director explained that because members of the camper population were from communities of color, they tended to express themselves through aggressive physical or verbal behavior, which also necessitated more adult supervision. In addition to counselors, a plan was put into place to ensure social worker coverage for each cabin group. This additional supervision seemed to enable the groups to spend

more time on the camp activities, and less time dealing with behavior problems because campers received more individual attention.

### **Accessibility**

Another way that feelings of reprieve and recreation were planned for at camp was through the accessibility of all activities, based on CFA's facilities. Gary was very impressed with the facilities:

There's nothing a camper can't do here. Like, for instance, I know the treehouse, they can get up to 10 wheelchairs up there at one time, which there are not many places that offer than kind of... There is not an activity here that a kid cannot do. Just that they can do anything.

CFA was very intentional about making camp "barrier-free," and the accessibility of camp was perceived by both campers and staff. I did not observe any instances of campers being thwarted in their efforts to participate in an activity (with the exception of the boy at the night time zip line activity as discussed earlier). Certain accessible supports were even incorporated into activities; for example, some campers chose to use the heavy-duty wheelchairs in the pavilion to play wheelchair basketball, even though they did not have mobility impairments.

Additionally, the medical facilities were a means of making the camp accessible to campers. Dr. Helen described them:

I mean, it's fabulous. You've got, sheerly from a medical standpoint, the cabins are air conditioned and well attended to and so that kids who are medically frail, can still have the opportunity to come. The medical center is well stocked and so

we can do injections. We have built good connections with the local emergency rooms as well as with LifeFlight and other things, and so it was all very well thought out at least from a medical standpoint in having the backup that you need to allow kids that perhaps are medically fragile to come to camp and, obviously, we hope that nobody is medically fragile anymore and that they're all doing well but if we have some kids who are they can still have as much of the camp experience as they want and that is great.

The medical and psychosocial teams were additional resources that supported campers' successful involvement in camp activities.

### **Freedom from Worry**

Campers were free of worry while at camp, which was another major reason that camp was a reprieve and opportunity for recreation. Nelson explained how camp offered such opportunities:

Well, like at home, I have to act different with my mom and brothers because I have responsibilities there. Like with my family, like my brothers have to act, like show them what they're supposed to do. But at camp I can do whatever I want, I can run around, like joke around, say what I want to say, that kind of stuff.

Gary supported this idea: "Out here they're just allowed to be kids, just do fun things, just to be themselves, just to cut loose and everything and not have to worry about anything." This freedom from rules was only perceived; there were several guidelines in place to ensure the campers' safety and appropriate behaviors.

Still, the activities were a less important reason that camp was enjoyed than was the sense of belonging to a group of caring people. Not only was this support felt within unstructured time, it was also felt within Teen Talk. Here, campers felt relieved of the burden of keeping their secret, and this made the Teen Talk program one of the most memorable experiences of camp:

‘Cause you get to talk with other people that know what you’re going through, and like they just have more, they know what you’re goin’ through and you have people to lean on. It just feels better knowing that you’re not the only one that has to deal with this by yourself (Cece).

Additionally, campers learned valuable information about living with HIV during Teen Talk that helped them feel more secure in their knowledge about it.

*Processes: Increasing Attitudes, Skills, and Knowledge*

The program processes that contributed most to the campers’ development of knowledge, attitudes, and skills were education through Teen Talk and non-Teen Talk education. Education arose through interactions with other campers and staff.

**Education Through Teen Talk**

This was the primary mechanism for the development of knowledge, attitudes, and skills in campers through the exchange of information. While it only took up four to eight hours out of approximately 120 possible hours spent at camp (depending on the summer), Teen Talk seemed to have a disproportionately large impact on this outcome; this was the only opportunity campers had to specifically discuss HIV during camp. The content of Teen Talk changed from year to year, and evolved based on the campers’

needs. For example, this year, several campers had questions about the reasons why they had to deal with HIV when their siblings or other relatives did not, and this will be incorporated into the topics for next year.

A Teen Talk facilitator explained that the sessions were planned based on what came up for campers the year before. Years ago Teen Talk was very informal, but the curriculum became more formalized over time, and was grounded in increasing interactions with doctors and social workers about appropriate exercises to include that would best reach and relate to campers. Facilitators explained that while campers *should* know the basic facts about HIV (i.e. it cannot be transmitted via kissing or mosquitoes), when they got to Teen Talk it became apparent that they really did not know as much as they were expected to by doctors and social workers. As discussed earlier, the facilitators were perceived as easy to approach with questions that campers might feel uncomfortable bringing to their social workers or doctors, and this created an easier atmosphere in which to share information.

Increasing technical knowledge about HIV was a major goal of Teen Talk. Information was shared about cells, transmission, how medications work, how HIV affects the body, and more. Junior Teen Talk topics tended to focus more on securing this basic information, and Senior Teen Talk topics focused on how to apply this information, such as how to use condoms correctly. The first night of Teen Talk was mandatory, but the other sessions were optional; the facilitators only wanted participants who wanted to be there. Usually, all campers attended, but sometimes two or three would stay back in their cabins.

### **Non-Teen Talk Education**

For youth ages 10-13, a new program was introduced this year called Tween Talk, which was facilitated by an AFH intern. She developed four 45-minute sessions on character development (including trust, respect, and compromise) that involved engaging activities. Some campers were aware of their HIV status and some were not, so HIV was not discussed in Tween Talk; the content was more generally “character development” rather than health education. As this was a new program this year and was provided to campers under the age group that was targeted in this study, it was unclear how Tween Talk contributed to the camp outcomes.

Counselors with campers 12 and older were instructed that if campers came back after Teen Talk and wanted to discuss their feelings about it that they should be aware of campers sharing disturbing or untrue information; if that happened, the psychosocial team should be contacted. The doctors did not want any “mini-Teen Talks” in the cabins to ensure that misinformation would not be transmitted. Additionally, if campers were distraught, the psychosocial team wanted to be contacted so that they could help the campers.

However, I noticed that there was an inconsistent message sent about the role of counselors in campers’ development of knowledge, skills, and attitudes. During the pre-camp meeting between social workers, doctors, and camp support staff, one doctor took a hard line approach that ALL questions about HIV should be directed to the medical team, especially the doctors because they had the most accurate information (apparently others such as nurses and medical students only *thought* they had the right answers).

However, during orientation on the day before the campers arrived, a Teen Talk facilitator instructed the counselors to “Just answer what you can.” This messaging conflict did not seem to become an issue during camp, however.

Campers explained several instances when they used the information they learned in Teen Talk at home, especially how to disclose their status to others. Many campers learned new techniques to take their medications; while they may have previously been shown how by their doctors, in the relaxed space of camp and the exposure to other youth taking the same medications, campers were more likely to internalize these techniques. Additionally, this information was reiterated and reinforced in the clinics after camp by the doctors with the campers.

### **Summary**

Four outcomes of camp and the processes that led to those outcomes were identified. At camp, youth had opportunities to experience caring people, develop a sense of belonging, feel reprieve and experience recreation, and increase their knowledge, skills, and attitudes. Outcomes were achieved through several processes within camp, particularly Teen Talk, storytelling, exposure to new ideas and people, and acculturation into a positive social context. The context of camp served an important developmental role in the lives of campers. The supports and opportunities for positive youth development found at camp were especially salient for youth with HIV/AIDS because of the secrecy, stigma, isolation, and lack of knowledge in other contexts outside of camp.

## CHAPTER V

### SUMMARY AND CONCLUSIONS

The purpose of this interpretive case study was to understand the outcomes associated with participation in the camp experience for youth with HIV/AIDS, and the processes within camp that might have influenced those outcomes at a camp. Other research on settings for youth development typically assumes universal processes for all youth; this study demonstrated the importance of and need for exposing youth with chronic illness to specific supports and opportunities for developmental outcomes. This study also highlighted unique issues faced by youth with HIV/AIDS. Additionally, other research on youth with disabilities such as chronic illness typically overlooks developmental outcomes in favor of narrowly focusing on youths' transitions to adulthood, and tends to rely on clinical settings rather than on other youth contexts. This study tied these two research fields together and examined the role that camp played in the development of youth with HIV/AIDS.

In the discussion of findings, I summarize *how* and *why* campers experienced various outcomes. This information is most suited for representation through a series of processes-outcomes charts that are presented in this chapter. For each of the four main outcomes associated with camp participation, I then discuss how this study shared connections to other related research and also explore some disconnections between the study findings and existing literature. Finally, I discuss implications of this study for theory, practice, and future research.



### **Summary of Findings**

Camp played a major developmental role in the lives of youth with HIV/AIDS. Campers felt isolated in their home environments due to (1) stigma about HIV/AIDS and (2) lack of support systems for their development. At camp, children felt a sense of belonging to a larger world that (1) gave them knowledge about HIV/AIDS and their lives and (2) cared about them. This experience led to coping skills and attitudes that resulted in hope for the future. Hope for the future in turn led to health and well-being. This was predicated on the notion that youth are “active agents in their own development” (Lerner, Theokas, & Jelicic, 2005), and that when exposed to opportunities for asset development, they will pursue them. The campers in this study typically had few other supports and opportunities in their lives for positive development; still, there appeared an underlying agency on the part of campers as they actively sought out what supports and opportunities were available.

Four thematic outcomes of camp emerged: (1) experiencing caring people, (2) developing a sense of belonging, (3) feeling reprieve and experiencing recreation, and (4) increasing knowledge, attitudes, and skills. Experiencing caring people consisted of five sub- themes: (a) the social context of camp is caring; (b) campers are caring in and outside of camp; (c) counselors are caring in camp; (d) people from camp are encouraging; and (e) campers are not judged. Developing a sense of belonging consisted of the following sub-themes: feeling isolated at home; being around similar others, and; feeling like camp is normal, a home.

Feeling reprieve and experiencing recreation consisted of the following sub-themes: camp activities are fun; camp is something that is anticipated and reflected on all year, and; there is a sense of freedom at camp. Increasing knowledge, attitudes, and skills consisted of the following sub-themes: adult life skills; anger and conflict management; confidence; disclosure attitudes and skills; learning and education; medication adherence; hopefulness; personal growth, and; other outcomes.

Each outcome had program processes associated with it. Processes that seemed to contribute most to the campers' experiences of caring people were long-term relationships, outside of camp support, exposure and storytelling, and Teen Talk (an education-based workshop). Processes contributing to campers' development of a sense of belonging were acculturation into Camp Hope, Teen Talk, medication taking, grieving, aging out of camp, and storytelling. Processes contributing to campers' experiences of reprieve and recreation were camp activities (including Teen Talk), planning for the needs of campers, accessibility, and freedom from worry. Processes contributing to campers' development of knowledge, attitudes, and skills were education through Teen Talk, and non-Teen Talk education.

Clearly, Teen Talk was a major process through which outcomes occurred. A key part of the camp experience was the existence of a safe space in which to share concerns and gather helpful information from similar others. Even though this program occurred for one to two hours three or four times during the week, the effects of it were far-reaching and long-lasting. This was likely due to the dearth of opportunities that campers had for similar engagement *outside of camp*. There was also a spillover effect from Teen

Talk into campers' interactions during other camp activities. The cultural context that was established during Teen Talk was transferred to other social interactions through camp. This acculturation included the establishment of a common ground among campers, group bonding, and social controls and expectations. Teen Talk was not viewed by campers a separate part of camp, but seemed synonymous with "camp."

Additionally, outcomes from Teen Talk emerged through the method of storytelling, which has particular significance in communities of color (Collins, 2000); nearly all campers were African American. As Collins explains, "Experience as a criterion of meaning with practical images as its symbolic vehicles is a fundamental epistemological tenet in African American thought systems," (p. 258). Relying on the oral tradition, information is best believed and internalized when it comes from others who have shared similar experiences, and *knowledge* gained through personally isolating methods such as books is deemed inferior to and less reliable than the *wisdom* gained from trusted others (Collins, 2000; hooks, 1981). While the purpose of this study was not focused on ethnicity-based communication styles, it appeared that there was a strong value and emphasis on the sharing of lived experiences as the impetus for personal growth and developmental advancement, and this was likely related to the fact that nearly all campers were African American.

The other major process by which outcomes occurred was through camper engagement in the fun camp activities. These activities were especially poignant for youth who typically did not have easy access to similar recreation opportunities at home due to perceived lack of availability or fear of stigma. For example, many people feel

uncomfortable swimming in a pool with someone with HIV due to an erroneous belief that the virus can be transmitted through water. Activity engagement was further supported through close physical contact with counselors; as the camp director explained, many of the campers were not touched or played with in their everyday lives. At camp, this “touch deficit” was ameliorated.

Camp offered a sense of *community* that was otherwise lacking in kids’ lives. Perhaps due to the increasing isolation of all youth in the presence of technology, dissolution of family networks, increasing globalization, and narrow focus on academic achievement, summer camp provided a remedy to feelings of loss and disconnection. In his personal account of his camp experiences, Michael Eisner, former CEO of the Walt Disney Company remarked, “When all is said and done, people of all ages want to be a part of something bigger and more important than themselves. More than anything else, this is the value that camp teaches kids. It offers them a perspective and provides them with a head start on the road to becoming fully human” (Eisner, 2005). While activities were an important source for outcome development, it was really the relationships campers built with each other and their counselors that fostered the outcomes. Through long-term relationships, connections with people from camp outside of camp, storytelling, and cooperative engagement in play, the social fabric of camp was knitted.

Interestingly, a major national study on how camp program components related to outcomes for campers did not show significant relationships between the two (Henderson, Bialeschki et al., 2007). While on the surface this was surprising and counterintuitive, the authors suggested that perhaps a better approach would be to

examine how the various camp components collectively worked together to influence outcomes, given that all camps in the study met or exceeded ACA accreditation standards. Additionally, it was possible that the measurement instruments and research design did not fully capture the relationships between variables. In the present study, it was difficult to linearly link one process to one outcome; more often, a unique combination of several processes influenced outcomes. These findings suggested that there are profiles of processes within individual camps, and that different process profiles may influence different sets of outcomes.

### **Outcomes-Processes Charts**

The findings in this study can best be represented through use of a series of charts that display the connections between each of the outcomes, their sub-themes, and the processes that influenced them. The charts are organized in the following way. The “Typical life situations and needs of campers” column describes the rationale and justification for the outcomes, processes and program components, based on the home contexts of campers. The “Outcomes associated with camp participation” column consists of one of the four main outcome themes. “Sub-Outcomes” are the sub-themes of each of the four outcomes. “Processes within camp that influenced outcomes” are those that are associated with each theme. “Program components that comprise the processes” are those structural and relational elements of camp that could be manipulated, and comprise the processes. The following discussion is organized by the four outcomes identified in this study: experiencing caring people, developing a sense of belonging,

feeling reprieve and experiencing recreation, and developing knowledge, skills, and attitudes.

First, the outcome of *experiencing caring people* was important in light of the home contexts of campers, and consisted of the sub-outcomes of a caring social context, campers caring in and out of camp, counselors caring at camp, and encouragement from people from camp. These sub-outcomes were primarily influenced by the camp processes of long-term relationships, exposure, storytelling, Teen Talk, outside-of-camp support, and camp activities. Each of these processes was comprised of related structural and relational program components. Table 5 highlights these connections.

Table 5. *Outcome 1: Experiencing Caring People.*

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers feel alone</li> <li>• Campers don't have many supports and opportunities for caring people in their lives</li> <li>• Lack of consistency and care in relationships at home</li> </ul>	1. Experiencing Caring People	1a. The social context of camp is caring	<ul style="list-style-type: none"> <li>• Long-term relationships</li> <li>• Exposure and storytelling</li> <li>• Teen Talk</li> <li>• Outside of camp support</li> </ul>	<p><u>Structural elements:</u></p> <ul style="list-style-type: none"> <li>• Interactions within activities</li> <li>• Nametags</li> <li>• Medical and psychosocial care and support</li> <li>• Planning for camper needs</li> <li>• Cabin placements (to ensure compatibility)</li> <li>• Physical safety</li> <li>• "Camp News Network"</li> </ul> <p><u>Relationship elements:</u></p> <ul style="list-style-type: none"> <li>• Familiar people</li> <li>• Warm greetings and interactions</li> <li>• Psychological safety</li> <li>• Maintenance of positive social norms, expectations for desirable and acceptable values and morals</li> <li>• Integration of efforts from counselors, doctors, psychosocial team</li> <li>• Opportunities to develop and practice social competencies</li> <li>• Mutual respect</li> </ul>

Table 5 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers feel alone</li> <li>• Campers don't have many supports and opportunities for caring people in their lives</li> <li>• Lack of consistency and care in relationships at home</li> </ul>	1. Experiencing Caring People	1b. Campers are caring in camp and outside of camp	<ul style="list-style-type: none"> <li>• Long-term relationships</li> <li>• Exposure and storytelling</li> <li>• Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Unstructured time in cabins</li> <li>• Interactions within activities</li> <li>• Memory books to share contact info</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Warmth, closeness</li> <li>• Attention</li> <li>• Encouragement of appropriate behavior, values, morals</li> <li>• Opportunities to develop and practice social competencies</li> <li>• Descriptions of overcoming adversities</li> <li>• Playful threats and sarcasm (attention)</li> </ul>
		1c. Counselors are caring in camp	<ul style="list-style-type: none"> <li>• Exposure and storytelling</li> <li>• Long-term relationships</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• High staff-camper ratio (1:2)</li> <li>• Continuity and consistency</li> <li>• Counselor selection and retention</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Role modeling/ guidance</li> <li>• Warmth, closeness, hugs</li> <li>• Attention</li> <li>• Flexibility based on individual camper needs</li> <li>• Predictable, available, and appropriate guidance from adults</li> <li>• Descriptions of overcoming adversities</li> <li>• Playfully transgressing rules and boundaries</li> <li>• Lack of emotional and physical distancing</li> </ul>
		1d. People from camp are encouraging	<ul style="list-style-type: none"> <li>• Camp activities</li> <li>• Outside of camp support</li> <li>• Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Challenging activities</li> <li>• Challenge by choice philosophy</li> <li>• Threads of connections between camp, clinic, to home</li> <li>• Knowledge about individual campers</li> <li>• Opportunities to develop and practice social competencies</li> <li>• Flexibility in scheduling based on camper needs</li> <li>• "Camp News Network"</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Individual attention</li> <li>• Trust</li> <li>• Descriptions of overcoming adversities</li> </ul>

Table 5 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers feel alone</li> <li>• Campers don't have many supports and opportunities for caring people in their lives</li> <li>• Lack of consistency and care in relationships at home</li> </ul>	1. Experiencing Caring People	1e. Campers are not judged	<ul style="list-style-type: none"> <li>• Exposure and storytelling</li> <li>• Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Teen Talk facilitators</li> <li>• Proximity to similar others</li> <li>• Opportunities to develop and practice social competencies</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Positive/kind social norms</li> <li>• Respectful attention and interactions</li> </ul>

There is a large body of research that highlights the importance of caring relationships as a developmental support in youth programs (e.g., Anderson-Butcher et al., 2004; Newton et al., 2007; Rhodes, 2004). Camp is an ideal setting for the development of such relationships due to the increased opportunities for unstructured and informal interactions between people as they go about daily routines in a cooperative living environment. Increased unstructured and informal interactions allow for higher levels of attention and support at camp than in school settings or after-school programs due to higher staff- camper ratios, greater amount of time available during a week at camp, and intimacy found within close living quarters such as cabins.

The importance of camp friendships for youth with chronic illness has been well-documented (Bluebond-Langner et al., 1991). In Bluebond-Langner et al.'s study, the camp relationships for youth with cancer were unlike those with their healthy peers



because they were characterized by qualities of empathy, understanding, and acceptance; however, campers also valued relationships with healthy peers because within these relationships they were free from attention to their illnesses, and the resulting anxiety. Friendship quality is also crucial to the psychological health of youth with chronic illness, as it has been shown to affect their physical well-being (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007).

In this study, campers did not mention that they viewed their doctors and social workers in a new and more approachable light; however, doctors and social workers identified this as a major strength and influence on campers both during and after camp. This lack of concordance in the “therapeutic alliance” (or helping relationship) has been demonstrated in other studies. For example, Bickman et al. (2004) found that there was a lack of correlation between therapists’ and youths’ views of the therapeutic alliance, and this remained constant no matter how long they knew or worked with each other. Still, the overall context of Camp Hope was perceived as caring, and campers seemed diffusely cognizant of medical and psychosocial staff as being a part of this caring context.

Experiencing caring people helps to build social capital (the collective value of all social networks in one’s life; Putnam, 2000). The creation and nurturance of connections with caring others is an important developmental support. Given that youth with chronic illness are more likely than their healthy peers to engage in risky behaviors (Miauton et al., 2003), a caring social network is crucial to supporting their psychological health and ultimate well-being.

Second, the outcome of *developing a sense of belonging* was important in light of the home contexts of campers, and consisted of the sub-outcomes of feeling isolated at home, being around similar others, and feeling like camp is normal. These sub-outcomes were primarily influenced by the camp processes of opportunities for grieving, medication taking, Teen Talk, storytelling, aging out of camp, and acculturation. Each of these processes was comprised of related structural and relational program components. Table 6 highlights these connections.

Table 6. *Outcome 2: Developing a Sense of Belonging.*

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers feel alone</li> <li>• Campers want to belong to something bigger than themselves</li> <li>• Campers need to affiliate</li> </ul>	2. Developing a Sense of Belonging	2a. Feeling isolated at home	<ul style="list-style-type: none"> <li>• Grieving</li> <li>• Medication taking</li> <li>• Teen Talk</li> <li>• Storytelling</li> <li>• Aging out of camp</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Expanding knowledge about HIV</li> <li>• Taking meds in the open</li> <li>• Proximity to similar others</li> <li>• A place to go during the summers</li> <li>• Opportunities to share feelings</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Support for grieving</li> <li>• Freedom from need to disclose at camp</li> <li>• Identification with others</li> <li>• Membership in a social community</li> </ul>
		2b. Being around similar others	<ul style="list-style-type: none"> <li>• Teen Talk</li> <li>• Medication taking</li> <li>• Grieving</li> <li>• Storytelling</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Interactions within activities</li> <li>• Awareness of others</li> <li>• Opportunities for affiliation</li> <li>• Close social contact</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Sharing “the secret”</li> <li>• Discussing coping mechanisms and strategies</li> <li>• Hearing others’ experiences</li> <li>• Sharing life experiences and making them coherent</li> </ul>

Table 6 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers feel alone</li> <li>• Campers want to belong to something bigger than themselves</li> <li>• Campers need to affiliate</li> </ul>	2. Developing a Sense of Belonging	2c. Feeling like camp is normal, a home	<ul style="list-style-type: none"> <li>• Acculturation</li> <li>• Aging out of camp</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Formal and social rules for interactions</li> <li>• Graduation/formalizing transitions</li> <li>• Membership in a positive culture</li> <li>• Close social contact</li> <li>• Living arrangements (decorations, open facility design)</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Long-term relationships</li> <li>• Trust</li> <li>• Attention</li> <li>• Older age = higher social status and respect</li> <li>• Caring and attention</li> <li>• Feelings of support from respected others</li> <li>• Transgressing rules and boundaries</li> </ul>

After learning that octopuses gather stones and shiny objects and arrange them in “gardens,” Ringo Starr of the Beatles became delighted by this idea because “At the time I just wanted to be under the sea, too. I wanted to get out of it for a while,” (Dowlding, 1989, p. 283). In “Octopus’s Garden,” (1969) he sings of a magical place that conjures images of camp:

I'd like to be under the sea  
 In an octopus's garden in the shade  
 He'd let us in, knows where we've been  
 In his octopus's garden in the shade

I'd ask my friends to come and see  
 An octopus's garden with me  
 I'd like to be under the sea  
 In an octopus's garden in the shade

We would be warm below the storm  
 In our little hideaway beneath the waves

Resting our head on the sea bed  
In an octopus's garden near a cave

We would sing and dance around  
Because we know we can't be found  
I'd like to be under the sea  
In an octopus's garden in the shade

We would shout and swim about  
The coral that lies beneath the waves  
Oh what joy for every girl and boy  
Knowing they're happy and they're safe

We would be so happy you and me  
No one there to tell us what to do  
I'd like to be under the sea  
In an octopus's garden with you.

Starr's feelings of safety, connectedness, joy, and freedom parallel the experiences of campers in the "octopus's garden" of camp in which they did not have to worry about the "waves" of stigma, negative living environments, etc.

Developing a sense of belonging to a valued community is a major task of young people as they grow into adulthood. This need is especially important for youth who typically experience isolation in their everyday lives, such as those with chronic illness. Experiences of stigma associated with chronic illness further amplify this isolation. When the isolation is breached, however, the sense of relief and connection can be invigorating. Many studies have indicated the significance of developing relatedness with others (e.g. Gest, Welsh, & Domitrovich, 2005; Ryan & Deci, 2000; Sheldon & Bettencourt, 2002). Developmental Systems Theory (Lerner & Castellino, 2002) supports the existence and importance of supportive contexts to which people belong.

These contexts are theorized to work in concert with individuals, and this dynamic interplay is what drives human development.

The intentional use of camps to ameliorate the loneliness and isolation of youth with disabilities has been noted in other studies (Bluebond-Langner et al., 1991; Brannan et al., 1996; Goodwin & Staples, 2005; Meltzer & Rourke, 2005). For example, Goodwin and Staples (2005) explained that the participants with disabilities in their study felt that “connecting to others with disabilities helped them understand themselves better,” (p. 174). This idea was demonstrated in the present study, particularly regarding issues of grieving and disclosure.

That camp felt like “home” to the campers in this study is related to Gill’s (1997) conceptualization of processes within disability communities: (1) “coming to feel we belong” (integrating into society); (2) “coming home” (integrating with the disability community); (3) “coming together” (internally integrating our sameness and ‘differentness’); and (4) “coming out” (integrating how we feel with how we present ourselves). Campers identified with the values inherent in the social context of camp, and integrated themselves into the culture, which was perceived as a safe space, a refuge. This social space was so safe that it felt like home *should* feel - normal. In the documentary film “Camp Out,” gay Christian youth described their camp in such a manner, as “a sanctuary” away from the deleterious pressures of straight peer and traditional church contexts, and where everything was finally *normal* (Marcolina & Grimaldi, 2008).

A sanctuary in which to feel a sense of belonging is perhaps even more important in the lives of youth experiencing the profound effects of stigma than it is for those who face lesser feelings of isolation. The fear of labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001) were described by campers in this study as being pervasive in their lives. As Link and Phelan (2001) discuss, stigma is a likely key determinant of many life chances such as psychological well-being, health, and housing. While these risks can be thought of as being general to all populations, the stakes are higher for youth with HIV/AIDS. The HIV/AIDS epidemic has long been associated with the taboo subjects of drugs and sex (Forsyth, 2003); many feel that the virus is deserved because of one's degenerate behavior. Additionally, Forsyth notes that one's internalized stigma may be greater than the stigma imposed by society.

As such, topics of stigma and disclosure appeared frequently in campers' descriptions of why a sense of belonging at camp was so important to them. Given the biopsychosocial nature of HIV/AIDS (Brown et al., 2000), a variety of interacting needs and issues emerged for campers during camp. Experiencing a sense of belonging to a supportive social network may help to guard against the increased chances of depression, anxiety, and other psychiatric disorders that are found in adults with HIV/AIDS (Brown et al., 2000). Gaining information and inspiration to cope with the challenges of the disease, combined with those of growing into adulthood is predicated on the availability of a trusted and caring community. But the existence of such a community is not enough; youth need to actively seek support from others to fully benefit from the

supports and opportunities made available in the community. In a relaxed setting such as camp, the encouragement to seek this support is better internalized.

Third, the outcome of *feeling reprieve and experiencing recreation* was important in light of the home contexts of campers, and consisted of the sub-outcomes of fun camp activities, anticipating and reflecting on camp all year, and experiencing a sense of freedom at camp. These sub-outcomes were primarily influenced by the camp processes of camp activities, accessibility, Teen Talk, planning for the needs of campers, and freedom from worry. Each of these processes was comprised of related structural and relational program components. Table 7 highlights these connections.

Table 7. *Outcome 3: Feeling Reprieve and Experiencing Recreation.*

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers lack real and perceived access to recreation facilities and opportunities</li> </ul>	3. Feeling Reprieve and Experiencing Recreation	3a. Camp activities are fun	<ul style="list-style-type: none"> <li>• Camp activities</li> <li>• Accessibility</li> </ul>	<p><u>Structural elements:</u></p> <ul style="list-style-type: none"> <li>• Flat terrain</li> <li>• Accommodations for variety of abilities</li> <li>• Activity options explicitly provided</li> <li>• Open spaces for maneuvering wheelchairs</li> <li>• Fully equipped health center</li> <li>• Medical Team to organize meds</li> <li>• Transparent continuous program improvement through feedback and evaluations</li> <li>• Age-appropriate activities that are mildly-moderately challenging</li> <li>• New activities each year</li> <li>• Adequate rest times to allow quality engagement</li> </ul> <p><u>Relationship elements:</u></p> <ul style="list-style-type: none"> <li>• Attention to individual needs</li> <li>• No- and low-pressure encouragement to try new things</li> <li>• Watching others participate</li> </ul>

Table 7 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers lack real and perceived access to recreation facilities and opportunities</li> </ul>	3. Feeling Reprieve and Experiencing Recreation	3b. Camp is something that is anticipated and reflected on all year	<ul style="list-style-type: none"> <li>• Teen Talk</li> <li>• Planning for the needs of campers</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Yearbooks</li> <li>• Certificates and awards</li> <li>• Gifts from counselors and other staff</li> <li>• Web-based photo blog (Florida)</li> <li>• Emails to counselors regarding opportunities for social and volunteer activities</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Communication outside of camp between campers</li> <li>• Discussing camp with social workers and health care providers</li> </ul>
		3c. There is a sense of freedom at camp	<ul style="list-style-type: none"> <li>• Freedom from worry</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Basic life necessities are available (food, shelter)</li> <li>• Opportunities to engage in intrinsically motivated activities</li> <li>• No requirements or duties while in camp</li> <li>• No contact with home</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Everyone knows “the secret”</li> <li>• Encouragement to play and relax</li> <li>• Challenge by Choice philosophy</li> <li>• Focus on the “now”</li> </ul>

To varying degrees, the outcome of feeling reprieve and experiencing recreation at camp has been identified in nearly all studies conducted in camps with youth with disabilities, as well as studies with more general populations (Brannan et al., 1996; Fullerton, Brandon, & Arick, 2000; Goodwin & Staples, 2005; McAuliffe-Fogarty et al., 2007; Michalski et al., 2003). The desire for this outcome for campers stretches back to the genesis of the organized camping movement, and was a key reason for the establishment of summer camps (Ramsing, 2007). This study demonstrated that the



outcome of feeling reprieve and experiencing recreation at camp was especially salient for youth with HIV/AIDS, who lacked such opportunities outside of camp.

Experiencing reprieve from stress and opportunities for recreation is important for all people, for it leads to health and well-being. For example, Hutchinson, Loy, Kleiber, and Dattilo (2003) found that for program participants with spinal cord injury and chronic illness, leisure activities buffered the effects of their immediate life stressors and also sustained their coping efforts. As Caldwell (2005) explains, leisure is therapeutic because it supports health through the *prevention* of, *coping* with, and *transcending* negative life events. In the present study, camp was viewed as a preventative resource for campers, especially by adults associated with the camp. The general consensus was that campers' potentially negative life choices and behaviors would be prevented through the social networking and connections, education, and exposure to positive supports and opportunities within camp. This was especially true for behaviors associated with medication adherence, anger management, and disclosure skills. The process by which this prevention was seen to occur was through shared coping strategies, such as how to disclose, take certain medications, and deal with grief from the loss of loved ones, as well as a broader approach to coping with living with HIV. Finally, camp was also a method by which to transcend the negative life events faced by campers. Some campers (especially older ones) seemed to indicate that having HIV/AIDS caused them to find a deeper, more profound meaning in life. The process of coming to terms with having HIV/AIDS was significantly and positively altered by their camp participation.

Camp was also a source of reprieve and recreation because it provided opportunities to experience flow and positive affect (Csikszentmihalyi, 1990). While the activities were not overly challenging to youth, they were able to engage fully in them, become distracted from other concerns in their lives, and feel free of stress. Participating in new recreational activities at camp provided avenues for maintaining physical health, interacting socially, and reducing stress.

In camp was a sense of control and choice not otherwise found in other parts of their lives due to great uncertainty over life events. This idea has been conceptualized as “sense of coherence” by Antonovsky (1993), and defined as “a way of seeing the world which facilitated successful coping with the innumerable, complex stressors confronting us in the course of living” (p. 725). A sense of coherence consists of three components: sense of comprehensibility, sense of manageability, and sense of meaningfulness. Relaxed engagement in recreational activities provided an open space in which campers developed a sense of coherence and contemplated how to comprehend, manage, and make meaning from their diagnosis through social interactions involving hearing others’ stories about their life experiences.

Other studies examining the role of leisure in the lives of people living with HIV/AIDS have found that leisure and recreation activities are important for coping with the negative effects of the diagnosis and increasing health and quality of life (Caroleo, 2001; Florindo, 2007; Sausser, Dattilo, & Kivel, 2000). For example, Florindo (2007) found that leisure time physical activity helped prevent fat accumulation in people with HIV/AIDS on highly active antiretroviral therapy (HAART). Sausser, Dattilo, and Kivel

(2000) explored leisure in the lives of people with HIV/AIDS and found that there were physical, mental, and structural factors that influenced leisure participation, and also that leisure was used as a way to negotiate perceptions of themselves. In Caroleo's (2001) ethnographic study, through participation in a therapeutic recreation program, participants reported an increased ability to cope with anxiety attacks, and that they found a sense of community within the program. While these studies were conducted with adults and not youth, implications can be drawn that can apply to youth. The findings from the above studies suggest that people living with HIV/AIDS have unique experiences within leisure and recreation contexts, and that providers should be responsive to the needs of participants as well as intentional about using their programs to foster supportive participant outcomes, particularly coping outcomes.

Simply being in a temporal and physical space with other people who "knew your secret" was a source of relief for campers in this study. Free of worry about how best to disclose and if such disclosure would result in negative effects, campers were able to take a break from this very trying concern and could better experience the activities camp had to offer. These feelings of reprieve and opportunities for recreation opened up campers to more readily accept information during camp, including increasing knowledge and skills through Teen Talk, building personal competencies, and considering alternate attitudes.

Fourth, the outcome of *increasing attitudes, skills, and knowledge* was important in light of the home contexts of campers, and consisted of the sub-outcomes of adult life skills, anger and conflict management, confidence, disclosure attitudes and skills,

learning and education, medication adherence, hopefulness, personal growth, and other outcomes. These sub-outcomes were primarily influenced by the camp processes of education inside and outside of Teen Talk. Each of these processes was comprised of related structural and relational program components. Table 8 highlights these connections.

Table 8. *Outcome 4: Increasing Attitudes, Skills, and Knowledge.*

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
<ul style="list-style-type: none"> <li>• Campers need to better understand HIV in order to make healthy decisions</li> <li>• Campers have limited opportunities for education in their lives</li> </ul>	4. Increasing Attitudes, Skills, and Knowledge	4a. Anger and conflict management	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Presence of psychosocial team</li> <li>• Camp rules</li> <li>• Energy-expending camp activities</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Group norms</li> <li>• Long-term relationships</li> <li>• Knowledge of others' life experiences so that empathy was formed</li> </ul>
		4b. Confidence	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Challenge By Choice philosophy</li> <li>• Climbing tower and zip line</li> <li>• Disclosure skills and attitudes</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Listening to others</li> <li>• Role modeling</li> <li>• Being with similar others</li> <li>• Encouragement by trusted others to overcome problems</li> </ul>
		4c. Disclosure attitudes and skills	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Teen Talk discussions</li> <li>• Role playing</li> <li>• Facilitated by nonjudgmental adults</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Storytelling</li> <li>• Problem solving with others who understand</li> <li>• Lack of judgment about one's decisions</li> </ul>

Table 8 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
		4d. Learning and education	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Teen Talk sessions</li> <li>• Facilitated by nonjudgmental adults</li> <li>• Opportunities to help others</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Trust in others</li> <li>• Role modeling</li> <li>• Lack of judgment about one's state of knowledge</li> <li>• Desire to help others</li> </ul>
<ul style="list-style-type: none"> <li>• Campers need to better understand HIV in order to make healthy decisions</li> <li>• Campers have limited opportunities for education in their lives</li> </ul>	4. Increasing Attitudes, Skills, and Knowledge	4e. Medication adherence	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Watching others take medications</li> <li>• Facts about side effects</li> <li>• Facts about importance of adherence</li> <li>• Presence of health care providers from home clinics</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Long-term relationships</li> <li>• Encouragement from others to take meds</li> <li>• Advice about handling side effects of particular meds</li> <li>• Advice about injecting or swallowing meds</li> </ul>
		4f. Hopefulness	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Education about life chances that counteract negative views</li> <li>• Traditions in camp – most things staying the same year after year</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Long-term relationships</li> <li>• Seeing people stay healthy</li> <li>• Encouragement from others to stay healthy</li> </ul>
		4g. Personal growth	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Challenging activities</li> <li>• Opportunities for personal reflection</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Role modeling</li> <li>• Long-term relationships</li> <li>• Sharing feelings with others</li> <li>• Meeting and interacting with new people</li> </ul>

Table 8 Continued.

Typical Life Situations and Needs of Campers	Outcome Associated with Camp Participation	Sub-Outcomes	Processes Within Camp That Influenced Outcomes	Program Components That Comprise the Processes
		4h. Other outcomes (self-esteem, finding dating partners, thinking of others before themselves, structure)	<ul style="list-style-type: none"> <li>• Education through Teen Talk</li> <li>• Education outside of Teen Talk</li> </ul>	<u>Structural elements:</u> <ul style="list-style-type: none"> <li>• Interactions with other cabins</li> <li>• Interactions with campers from other cities and states</li> <li>• Dances</li> <li>• CIT program</li> <li>• Consistent daily and weekly schedule</li> <li>• Rules and traditions</li> </ul> <u>Relationship elements:</u> <ul style="list-style-type: none"> <li>• Patient instructors</li> <li>• Believable encouragement from trusted others</li> <li>• Sharing a common ground (HIV)</li> </ul>

Such outcomes in the domains of knowledge, skills, and attitudes as listed above have been found in other studies as well (e.g., Fredricks & Eccles, 2006; Henderson, Whitaker et al., 2007; Thurber, Scanlin, Scheuler, & Henderson, 2007; Walsh, 2007). Several researchers have attempted to categorize these types of outcomes, such as *protective factors* (Jessor, 1993; Witt & Crompton, 1997), the Search Institute's rubric of the *forty developmental assets* (Scales et al., 2000), and America's Promise's rubric of the *six C's* of competence, confidence, connection, character, caring, and contribution (Lerner, Lerner et al., 2005).

Two outcomes stood out as particularly salient for campers: disclosure skills and attitudes, and medication adherence. These two outcomes are well-discussed in the literature on youth with HIV/AIDS, as they directly relate to the medical aspects of the illness (Brown et al., 2000; Lyon & D'Angelo, 2006; Naar-King et al., 2006; Steele et

al., 2007). This study adds to the literature in that it takes a recreation-based (rather than medical-based) approach to understanding issues of disclosure and adherence in youth, and suggests that camp can be an effective forum for education and empowerment regarding these issues.

All of the developmental outcomes in the present study overlap and are intertwined. Not surprisingly, they emerged from similar processes: Teen Talk education and non-Teen Talk education. As discussed earlier, these outcomes were supported through the relaxed atmosphere of camp; while education occurred, it was not deemed boring by campers and was threaded throughout the camp experience via formal (Teen Talk) and informal, spontaneous interactions. Improvements in youth development outcomes were evident, and were based on a level of intentionality in educational programming goals from the camp administrators, and medical and psychosocial teams. This was especially important given that most campers had few opportunities for developmental supports and opportunities outside of camp.

Intentionality in youth programs is a key element of how camps plan and achieve their goals through the development of a particular structure in which to do so (Bialeschki & Lyons, 2006). Walker, Marczak, Blyth, and Borden (2005) describe intentionality in the following manner:

The theory of *developmental intentionality* focuses on the design and daily implementation of effective learning opportunities for young people. First, it holds that programs are most effective when attention to long-term developmental outcomes for adolescents permeates every aspect of the program;

thus, intentionality is given center stage both in the design of learning opportunities and in the philosophy guiding youth worker interaction with youth. This attention should be directed not on shaping youth, but on shaping learning opportunities that help youth shape themselves. Following from this, a second precept of the theory is that youth are most likely to achieve desired developmental outcomes when they are actively engaged in their own learning and development. The program goals may originate from the organization and the youth workers, but young people need to be active collaborators in selecting strategies and defining the specific learning opportunities in order to create and sustain youth engagement. A third precept of the theory is that youth engagement results from a good fit between young people and the learning opportunities they take part in. Both the philosophy and the design of youth programs need to give special attention to creating this fit (p. 400).

The three precepts of intentionality, engagement, and good fit were readily apparent in Camp Hope's organizational processes. At Camp Hope, the presence of the eight developmental outcomes listed above was enabled through the thread of intentionality that was woven throughout the camp program. There was a shared value among the staff to focus on arranging different camp elements in order to meet camper needs. While this was done with different emphases on meeting campers' *developmental* needs based on the stakeholder group (e.g., counselors wanted them to enjoy themselves, doctors aimed for medication adherence), campers were quite clear that camp provided



them the supports and opportunities for growth and improvement in various developmental areas.

Examining *how* outcomes are developed is a topic of interest for most youth programs. The study of program processes that are associated with youth outcomes is indicative of an emerging agenda within the positive youth development research community. A few researchers have delineated various program components found during their studies. Table 9 represents the findings from these studies. Program components marked with an asterisk indicate those components also found in the current study.

Table 9. *Processes Research.*

Author(s)	Date	Name of study	Program components
Eccles and Gootman	2002	Community programs to promote youth development	Physical and psychological safety* Appropriate structure* Supportive relationships* Opportunities for belonging* Positive social norms* Support for efficacy and mattering Opportunity for skill building Integration of family, school, and community efforts*
Mahoney, Eccles, and Larson	2004	Processes of adjustment in organized out-of-school activities: Opportunities and risks	Supervision from and enduring relationships with supportive adults* Opportunities for positive relationships and peer social exchanges* Provision of challenging, desirable, skill-focused activities

Table 9 Continued.

Author(s)	Date	Name of study	Program components
Henderson, Powell, and Scanlin	2005	Observing outcomes in youth development: An analysis of mixed methods	Amount and intensity of program engagement of campers* Transparent reasoning offered from directors and staff for why the program was as it was* Quality of the program activities in terms of congruency between what staff and campers wanted Physical structures (e.g., activity opportunities, layout of the camp, unit organization) that enabled certain kinds of interaction* Amount and level of supervision in program activities and free time* Social interactions between staff and campers, and campers and campers* Opportunities youth had to choose the level of participation with which they felt comfortable* Means for travel between activities* Hugs, easy laughter, relaxed tone of interactions, knowing of and calling of first names* Staff relations to each other and levels of support offered to each other Size of activity groups, age groupings, camper-staff ratios, different skill levels, and choices of available opportunities* Rules* Cultural competence and sensitivity to inclusion by staff, campers, programs Standards for behavior, norms: paying attention to each other, use of language, use of behavior management* Decision-making power Opportunities for staff and self- improvement Program skills Social skills* Appreciation for camp elements
Carruthers	2006	Processes and outcomes of an after-school program for adolescent girls	Verbal persuasion* Exposure to role models* Supportive leaders* Adults with high expectations who encourage personal responsibility and decision making, provided opportunities for developing self-awareness and competence, and model transformation through adversity*
Henderson, Bialeschki, Scanlin, Thurber, Whitaker, and Marsh	2007	Components of camp experiences for positive youth development	Contact and leadership from trained staff, and their supportive relationships with campers* Program mission, structure, strategic planning and improvement* Accountability Outcomes assessment Opportunities for skill building Camp director experience, education, and commitment* Staff training and their enhancement of supportive relationships Staff desire to influence campers' lives High staff return rate* Diversity of staff High ratio of staff: camper* Training time devoted to goals of camp Provision of camper choices

Table 9 Continued.

Author(s)	Date	Name of study	Program components
High/Scope Educational Research Foundation (Akiva & Jones)	2007	Youth Program Quality Assessment Handbook	<ol style="list-style-type: none"> <li>1. Youth voice and governance</li> <li>2. Professional learning community</li> <li>3. Safe environment: psychological and emotional safety*, program space and furniture*, healthy food and drinks*, physically safe environment*, emergency procedures*</li> <li>4. Supportive environment: encouragement*, skill building*, active engagement*, reframing conflict*, session flow*, welcoming atmosphere*</li> <li>5. Interaction: lead and mentor, be in small groups, partner with adults, experience belonging*</li> <li>6. Engagement: plan, make choices, reflect*</li> </ol>
Daud and Carruthers	2008	Outcome study of an after-school program for youth in a high-risk environment	<p>Positive interactions*</p> <p>Activities that balanced skill acquisition with fun</p> <p>Cooperative activities*</p> <p>Students helping each other*</p> <p>Creation of emotionally respectful social space*</p> <p>Differences in nurturing levels</p> <p>Safety*</p> <p>Learning in a fun environment</p> <p>Staff show genuine interest and support = nurturing</p> <p>Role modeling*</p> <p>Discussions and opportunities to practice behaviors</p> <p>Positive reinforcement and encouragement*</p> <p>Exposure to a variety of opportunities for success*</p> <p>Instruction – creative, engaging, innovative, new skills</p> <p>Challenge – program and social competence</p> <p>Discuss future options</p>

The current study did not aim to reproduce or test its findings against those of these other studies. Rather, they are highlighted to demonstrate that in any given program, there is a set of outcomes and processes that are unique to that program. Still, this study demonstrated that there were categories of processes within youth development programs that needed to be articulated and intentionally manipulated to foster the desired outcomes for youth.

Taking a holistic approach, the existence of Camp Hope itself could be thought of as a meta-process. For campers, having a sense of connection to the concept of Camp Hope as a place to be with similar others who understood them was a valuable asset in their lives. Campers looked forward to the six days out of the year during which they could be themselves. Some may argue that having a “segregated” camp for youth with HIV and AIDS hinders their successful integration into larger social worlds and prevents others from developing knowledge and improving attitudes that could reduce or eliminate stigma (e.g., Dattilo, Kleiber, & Williams, 1998). Providing “option-rich” integrated recreation environments for people with and without disabilities is thought to lead to self-determination and empowerment for all (Wall & Dattilo, 1995). While this may be true in some situations and for some disability populations, the present study demonstrated that having a place to experience reprieve from the stress of keeping the secret of HIV was a key element in facilitating positive outcomes for participants. If HIV-negative campers were present, it is highly unlikely that campers would have developed the outcomes they did because they would have felt as constrained in freely sharing their HIV-related experiences as they do in school and their home communities. Camp provided youth important means to affiliate with similar others.

### **Disconnections with Existing Literature**

While this study added strength to other camp and youth development research, there were some missing links as well. Interestingly, several outcomes that were found in other empirically-based studies on camps were *not* identified in the present study. Outcomes and camp processes that were missing include: leadership, camper

engagement in planning activities, structured opportunities to connect outside of camp, training in positive youth development principles, experiences in nature, and recreational skill building.

Camp Hope had an absence of a few common procedures found in most camps. For example, there were no opportunities for campers to take on leadership positions, other than the CIT program (which was perceived as more of a counselor-support system rather than a camper leadership position). Some camps provide structured opportunities for camper engagement in the program planning process (such as through camper councils or having individual campers sign up for their own activities); Camp Hope did not use such a process. As such, there were few opportunities for camper “voice and choice.” The opportunities that did exist were to provide activity feedback to CFA, and to choose additional “pick-its.” Camp seemed to be responsive to campers’ activity preferences, but there were no opportunities for campers to be proactive about their needs and wants. Regardless, there was no indication that campers wished for more autonomy; they seemed satisfied with the adults’ high level of control over their camp experiences.

Another common camp procedure is offering campers a structured way to stay connected after camp is over, such as through mailings, reunions, or web-based social networking. Camp Hope intentionally refrained from doing this to ensure that there was no inappropriate involvement in campers’ lives from counselors, and because it was perceived as being too difficult to gather campers living in unstructured and chaotic situations. Regardless, an underground network of campers emerged, and they kept in

touch through phone calls and text messaging. This network was an important support and coping system for youth.

Training and support of counselors and other staff had a strong “behavior management” focus; there was little or no “positive youth development” approach. The orientation of most camp staff (especially doctors and social workers) seemed to be that campers’ behaviors must be controlled. There was no staff-level talk of goals or desired outcomes for campers, other than when I interviewed staff and asked those specific questions. During my observations and interviews, there emerged disparate beliefs among stakeholders about the goals of camp that ranged from pure fun to education to building life skills. Still, while this incongruence was seemingly profound, it appeared to have little or no effect on the outcomes of camp for campers.

The setting of camp is often used intentionally to ensure that youth have exposure to nature and the outdoors. The traditional idea of “camp” typically carries visions of campfires, primitive living areas, trees, trails, and other natural features. While the CFA site had most of these features, campers were not encouraged to explore them or given access to them. Surprisingly, campers were instructed to stay on the sidewalks and not to walk on the grass because the grass could not handle hundreds of youth each summer walking on it, and because CFA had recently spent a lot of money to refurbish the cement sidewalks and wanted campers to use them. When I asked the campers why we could not walk on the grass, I was told that it was because there were snakes in the grass. There were no environmental education programs offered, and no opportunities for nature exploration or satisfaction of curiosity about the outdoors. It was possible to

be at camp the entire week without stepping off of cement or touching something that was not human-made. It should be noted however that during the previous summer I observed nature education programs conducted during camp; it was likely that none were held during Camp Hope in the present study because of CFA staff turnover during that summer.

The activities that CFA offered were one-shot activities that lasted 45 minutes (or less if the group was running late, which was typical). As such, there were no opportunities to improve any specific skills or gain competence in an activity. There was a reliance on the activity being new and unique to the campers to meet the need for optimal challenge, and this appeared to be acceptable to campers. Still, the campers gained skills for disclosure and taking medication, which seemed to indicate that some levels of competence were experienced by campers, albeit not skills in the recreational activities.

Common camp processes such as opportunities for autonomy, skill building, nature exploration, and leadership were missing from youth's Camp Hope experiences. Even so, it appeared that these opportunities were less important than were the camp opportunities to build relationships with others and to relax.

### **Alternative Explanations**

Yin (2003) suggests that when employing case study methodology, alternate explanations for findings should be investigated and considered. In this study, there was a commingled rival explanation (i.e. the medical and psychosocial teams are the driving force behind the development of camper outcomes) and a super rival explanation (i.e. the

overall health care system of an individual camper is alone responsible for campers' outcomes). These alternate explanations can be represented as the possibilities that:

1. There are sets of outcomes and attendant processes other than what I found;
2. The medical and psychosocial support systems are actually the driving forces of camp, and counselors make no difference;
3. The internalization of outcomes comes from out-of-camp processes (the clinic, post-camp communication with friends, camp as one minor treatment option) or;
4. Camp has a negative effect on campers. For example, anxiety may become heightened as campers think more about their diagnosis and how alone they feel at home. Also, the confidence to disclose more freely could result in poor reactions to the disclosure, resulting in stress and loss of friendships. The lack of social relationships at camp may have further isolating effects that negatively influence youth's adjustment in other contexts. For example, campers such as Kevin and Milton, who did not seem to have much of a sense of belonging to their peer community at camp, might generalize their failure to connect with camp peers to peers in other contexts in their lives such as school. This could result in poor adjustment to school and lessened academic outcomes, for example. Negative iatrogenic effects of camp are quite possible, and worthy of future investigation.



Certainly, more research is needed to fully investigate these possible alternate explanations. However, there is some assurance that what has been represented in this study is valid and reliable, based on the methodologies used to gather and analyze data.

### **Implications for Theory**

The contribution of this study to the area of positive youth development was that it helped articulate how supports and opportunities found within the camp context relate to youth development outcomes, and delineated the processes and conditions that promote positive youth development in youth settings such as camp. Each camp has (and should have) its own outcomes and associated processes, and circumstances prevent the ability to generalize this study to *all* camps. Still, the findings from this study suggested a theoretical model of program participation elements.

These findings strengthen the connections within the framework of positive youth development. Resting on the assumption that youth are active agents in their own development, this study showed that when youth are exposed to supports and opportunities for development, they will engage them. Often, staff members overlook the agency of youth when considering the influence of their programs; youth are seen as passive recipients of services and outcomes. This study serves as a reminder that youth actually interact with programs, and absorb the experiences in unique and individual ways. This further reinforces the Developmental Systems Theory that youth are active agents in their own development, and that there is a synergistic and dynamic interplay between individuals and their contexts that can advance thriving (i.e. relative plasticity and adaptive regulations) in youth (Lerner et al., 2003).

This study also suggested that while it is important to be intentional about the types of outcomes desired for youth, it is also quite likely that it is not necessary to address all potential outcomes within a program in order to maintain a strong impact on youth. For example, in this study, campers seemed satisfied with low or no engagement in the planning process. This was also found in another study on camp supports for autonomy, relatedness, and competence; having an opportunity for autonomy was not a major reason campers were interested in camp (Gillard, Watts, & Witt, 2009). Deciding which outcomes for participants that programs will intentionally focus on, given the resources available, is a matter to be carefully considered by youth-serving organizations. No one program can achieve every possible youth development outcome.

Additionally, this study added to the literature on youth with chronic illness. Often, health care providers narrowly focus on the medical aspects of the illness, and neglect the other parts of youth's lives. This study highlighted that there is a wider array of issues that youth face as they cope with growing up with a chronic illness. Findings supported the idea that a variety of methods and holistic approaches are necessary to fully educate and support youth in their development. This study also linked the disability and youth development literature. To employ a public health or social work perspective would have uncovered only part of the outcomes associated with camp participation, particularly medication adherence and adult life skills. Employing a positive youth development perspective allowed other outcomes to emerge. Additionally, employing a recreation and leisure studies perspective allowed closer examination of the social and structural processes within the camp program that

influenced these outcomes, and relied less on the dyadic relationship between doctor or social worker and patient or client.

Finally, this study strengthened the notion that camp can be an important developmental support in the lives of youth. In an era of decreased funding for social programs such as after-school programs and camps, this study showed that camp can be a necessary developmental support for youth, especially those with chronic illness such as HIV/AIDS.

### **Implications for Practitioners**

Understanding the role that contexts such as camp play in the development of youth is crucial to supporting administrators and staff of youth-serving organizations in their efforts to optimize outcomes for young people. Additionally, it illuminates the “black box” program processes that are often overlooked in the quest for determining outcomes of participation. Beginning with the end in mind, camp administrators can manipulate different program components to influence the processes that lead to desired outcomes.

This study also highlighted that camp can be a powerful and supportive experience for youth with HIV/AIDS, a population about whom little is known outside of clinical and social work settings. The following recommendations for practitioners are organized around the four main outcomes found in this study.

Opportunities for campers to *experience caring people* can be planned for in every domain of camp, especially through staff selection and training procedures, establishment of ground rules in educational sessions such as Teen Talk, cabins, and

activities, and outside of camp. Staff should subscribe to the positive youth development approach and be encouraged to aim to influence youth's long-term developmental outcomes through camp. At Camp Hope, Teen Talk did a good job of establishing ground rules that spilled over into other interactions within camp; perhaps reinforcement of these rules could be conducted in other camp arenas. Given that this study showed that camp was a major influence on youth, it makes sense to provide for additional opportunities for youth to connect with others through the medium of camp. Although campers formed friendship networks outside of camp, it was possible that some of the campers on the outer edges of social groups (such as Kevin and Milton, for example) might have lacked access to these networks. To ensure equal access to social networks after camp, formal and informal opportunities for further relationship building and nurturing could be provided for campers by camp administrators. Doing so would provide further contact between the positive social context of camp and individuals, as well as provide opportunities to teach others about HIV/AIDS through advocacy and educational efforts. This would also influence the development of a sense of belonging to a larger, supportive community.

Opportunities to *develop a sense of belonging* are already highly evident in the camp context due to its inherent characteristics. For example, the close living arrangements necessitate cooperative and agreeable approaches to existing with a group of people for several days. Participating in fun activities with old and new friends supports bonding. Recognizing that others have had similar experiences helps to stave off feelings of isolation.

Further opportunities could also include increased time to share concerns and information, ways for campers to discover similarities with other campers, and engaging in fun recreation activities that make these other goals palpable to youth. Supportive adults can foster interactions between campers and between campers and staff as well. Youth living with HIV/AIDS typically lack effective supports for their efforts to disclose their status to others and to adhere to medication regimens; camp can be an important intervention tool to support youth in these efforts.

Opportunities to *feel reprieve and experience recreation* are already in place at Camp Hope. What should also be considered is how to balance recreational and educational goals for campers, and how to intertwine learning opportunities in the fun and relaxing activities of camp. Camp could provide more opportunities to build physical recreational skills, as these skills may carry over into campers' lives at home and help to ameliorate campers' couch potato tendencies. Campers could also select certain activities in which to participate as individuals rather than groups so that they could feel a sense of choice and control in their camp experiences.

Several researchers have suggested that people with HIV/AIDS face unique barriers in their leisure and recreation (Grossman et al., 1994; Grossman, 1997; Pearce, 1994; Sausser et al., 2000). Yet, engagement in leisure and recreation can provide a sense of self-determination, coping, social involvement, identity development, and personal fulfillment that increases the quality of life. Specific recommendations for negotiating these barriers include:

- Adapting activities to account for fatigue issues;
- Increasing opportunities for structured and unstructured physical activity;
- Avoiding offering activities that are simply diversional or entertaining (Caroleo, 1994) by being intentional about desired developmental outcomes of participation;
- Supporting youth in determining and achieving leisure and recreation goals;
- Integrating leisure and recreation into all contexts in which youth are involved, such as clinics, hospice and other care facilities, home, and school; and
- Highlighting people with HIV engaging in various recreation and leisure activities as role models to encourage participation from others.

Opportunities to *increase skills, knowledge, and attitudes* can be more intentionally integrated into camp programming. For example, after each activity, a five minute debriefing session could be held so that campers reflect on their experiences. Nightly cabin-based debriefing sessions could also be conducted, perhaps by the psychosocial team or trained facilitators. These debriefing activities need not be limited to discussions; journaling, art, and other creative methods could be employed. These opportunities should be age-specific; that is, older campers are more open to self-reflection and sharing than younger campers, and would likely be more amenable to increased opportunities for increasing skills, knowledge, and attitudes.

### Future Research Directions

As discussed in the study limitations section in Chapter III, this study cannot be generalized to all camps, but there are some issues that warrant further investigation. These issues can be grouped into categories which are described next: organizational management and stakeholders, other types of camps, longitudinal studies, and investigation of camp processes and outcomes using other methods.

While not central to the current study, a misalignment between various stakeholders emerged from the data. For example, I observed several staff members commenting on what camp did for *them*, not necessarily what it did for the *campers*. Many staff members felt that camp should only be about fun for the campers, and did not see it as an opportunity for more intentional youth development. More investigation is needed on how these differences in perspectives and goals operate within camp, and how they do or do not influence campers. Additionally, more research could be conducted on the effects of camp on the adult staff, especially those who live with HIV/AIDS.

One limitation of this study was that it was conducted during one summer. Findings showed that there were influences on campers from their preexisting relationships with social workers and doctors. It would be interesting to examine how therapeutic relationships are influenced by camp by observing and interviewing campers, doctors, and social workers before and after camp, and more in depth during camp as well, perhaps using camper-social worker or camper-doctor as the unit of analysis. Additionally, more research is needed on how outcomes may change over time for campers, based on differences in developmental stages. In this study, there appeared to

be an additive effect regarding outcomes for those with the most time spent in camp. A longitudinal study, perhaps following a cohort of campers, would be helpful in examining these issues.

Another limitation of this study was that data from only one caregiver was collected. A stronger effort and focus on what caregivers think about camp would be helpful to round out the data from this study. Given that accessing caregivers of campers with HIV/AIDS is extremely difficult, a separate and intensive qualitative study is warranted. For example, data could be collected at campers' homes.

Other methods of investigating camp processes and outcomes besides the case study approach would be helpful. For example, quantitative methods to measure outcomes and processes would provide another perspective of the phenomenon of camp. Additionally, the findings from this study could be compared to other types of camps, such as those for youth with other chronic illnesses and disabilities as well as more camps for youth from the general population. Given that the camper population was about 95% African American, research with other ethnic groups is also warranted. Other fields of knowledge could also be applied in examining the experience of camp for youth; for example, using an interpersonal communication perspective could more closely explore how storytelling operated within the context of Teen Talk to encourage campers to freely disclose their feelings.

### **Conclusion**

This research was about the outcomes and processes that influenced them at a camp for youth with HIV/AIDS. Choosing a qualitative approach to investigating this



phenomenon was appropriate to better understand the experiences of this population, about who little is known, especially outside of clinical settings. I hoped to both inform the academic community as well as the camp community about the developmental role of camp for youth with HIV/AIDS, and to provide insights to those who aim to use camp as a tool for positive youth development.

I chose to focus on the topic of camp in my research so that I could find out what does and does not work in creating powerful developmental experiences for young people. In my professional experience as a camp director, I wrestled continually with these questions; one reason I sought further formal education was to understand what I had done right, and what I could have done better at camp. The findings from this study helped to answer some of these questions, albeit even more questions were generated.

I did not fathom in the beginning of this research how much my life would be permanently altered by this study. Talking with people about this research opened up many doors to frank discussions and education about HIV and AIDS. Like the campers, I too increased my skills, knowledge, and attitudes, and found a community with whom I plan to align myself in the future through research and volunteer work. There is still much to be done to learn how to better support youth with HIV/AIDS.

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## APPENDICES

## APPENDIX A

## CAMP DIRECTOR INTERVIEW GUIDE

(2007 CFA Program Evaluation)

**Semi-Structured Interview Guide – Camp Director**

*[Give all adult interview participants 2 copies of the consent form – have them sign both, and give them the extra copy]*

Hi, my name is \_\_\_\_ and I'm here because Texas A&M is conducting an assessment of Camp For All, and \_\_\_\_ camp was one selected as a camp to observe. I'd like to talk with you a bit about what outcomes you see happening for campers. We're looking at what sorts of things camp does for campers by talking to experienced staff as well as campers, and your input will be really helpful. Thanks for taking time to help us.

This should take around 15-20 minutes. I'll be asking you some questions about your perceptions of camp. Everything you say is totally confidential, and none of your answers will ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, please feel free to be totally honest and open– we really want to know what everyone here thinks so that we can improve camp. And, don't worry that anything you say here will get back to other staff, campers, or the administrative or Camp For All staff – I promise that what is said here, stays here. Is it ok with you if I tape record our interview? Do you have any questions before we start?

Camp Administrator Interview Questions

1. Which camp are you with?
2. How long have you worked with \_\_\_\_? In what capacity?
3. How did you become affiliated with this camp?
4. What is your level of involvement with \_\_\_\_ outside of camp?
5. What is a typical daily schedule? What is the weekly schedule?
6. Who are your staff? How are they trained?
7. How do staff interact with campers?
8. How do you prepare campers for camp?
9. Describe the types of campers who come to your camp? (Demographics, years of attendance, involvement in other programs or camps, typical in-camp issues)
10. Do you do any follow-up activities after camp (i.e. reunions)? If so, what?
11. Do campers stay in contact with each other, staff, and/or the program after camp?
12. What are the goals that your organization is trying to achieve for campers? How do you do that?
13. Why do you think campers come to this camp? What is their motivation to attend?

14. Why do campers return?
15. Do campers take anything from camp back to their “real lives?” If so, what?
16. How do you see camp impacting your campers?
17. What changes have you observed in campers?
18. What do you think caused those changes?
19. What do campers like about their experience here?
20. What don’t they like, or what do they wish were different?
21. Where do you see your program going in the future? (goals, camper base)
22. Are there any key people (people who have a strong understanding of the campers) in your organization or staff who you could direct me to in order to talk further?

## APPENDIX B

## CAMP STAFF INTERVIEW GUIDE

(2007 CFA Program Evaluation)

**Semi-Structured Interview Guide - STAFF**

*[Give all adult interview participants 2 copies of the consent form – have them sign both, and give them the extra copy]*

Hi, my name is \_\_\_\_ and I'm here because Texas A&M is conducting an assessment of Camp For All, and \_\_\_\_ camp was one selected as a camp to observe. I'd like to talk with you a bit about what outcomes you see happening for campers. We're looking at what sorts of things camp does for campers by talking to experienced staff as well as campers, and your input will be really helpful. Thanks for taking time to help us.

This should take around 15-20 minutes. I'll be asking you some questions about your perceptions of camp. Everything you say is totally confidential, and none of your answers will ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, please feel free to be totally honest and open– we really want to know what everyone here thinks so that we can improve camp. And, don't worry that anything you say here will get back to other staff, campers, or the administrative or Camp For All staff – I promise that what is said here, stays here. Is it ok with you if I tape record our interview? Do you have any questions before we start?

Partner Camp Staff Interview Questions

1. Which camp are you with?
2. How long have you worked with \_\_\_\_?
  - a. In what capacity?
3. How did you become affiliated with this camp?
4. What is your level of involvement with \_\_\_\_ outside of camp?
5. How does Camp For All fit into the guiding philosophy or mission of your parent organization?

*Now I would like to ask you some questions about the day-to-day operation of camp:*

6. What is a typical daily schedule?
7. Describe the types of campers who come to your camp?
  - a. (Demographics, years of attendance, involvement in other programs or camps, typical in-camp issues)
8. Do you do any follow-up activities after camp (i.e. reunions)?
  - a. If so, what?
9. Do campers stay in contact with each other, staff, and/or the program after camp?
10. How do the activities in camp support the goals of your organization?

11. Why do you think campers come to this camp?
  - a. What is their motivation to attend?
12. Why do campers return?
13. Do campers take anything from camp back to their “real lives?”
  - a. If so, what? If not, why not?
14. How do you see camp impacting your campers?
15. What changes have you observed in campers?
  - a. What do you think caused those changes?
16. What do campers like about their experience here?
17. What don't they like, or what do they wish were different?
18. Is there anything else that you want to share?

***Thank You!***

## APPENDIX C

## FOCUS GROUP INTERVIEW GUIDE

(2007 CFA Program Evaluation)

**Semi-Structured Interview Guide - CAMPERS**

*[Give all campers 2 copies of the assent form – have them sign both, and give them the extra copy]*

Hi, my name is \_\_\_\_ and I'm here to talk with you a bit about what your experiences at camp have been. Thanks for taking time to help us. We're looking at what sorts of things camp does for campers, and your input will be really helpful.

This should take around 15-20 minutes. I'll be asking you some questions about your experiences at camp. Everything everyone says is totally confidential, which means that none of your answers will ever be connected to your name. You can choose to not answer any question if you want, and you can leave at any time. Also, please feel free to be totally honest and open– we really want to know what everyone here thinks so that we can improve camp for other kids like you. And, don't worry that anything you say here will get back to your counselors or other staff, other campers, or your family – I promise that what is said here, stays here.

So that I don't have to spend a lot of time writing everything down, and instead be able to listen to what you're saying, is it ok with you if I tape record our focus group? I would also like to ask that after I ask each question, that everyone gets a chance to talk, and that one person speaks at a time – is that ok with you? Do you have any questions before we start?

A. First Year Campers

1. Have you attended other camps?
  - a. What were they like?
2. Do you do things with the people from this camp outside of camp?
  - a. What?
3. Why did you come to camp?
4. What do you think the goals of Camp For All are?
  - a. Why do you think (insert partner agency) works with Camp For All?
5. What do you like most about camp?
6. What don't you like, or what would you change about camp?
7. What are the staff like?
8. What are the activities like?

9. Did you do anything new here?
  - a. Activities, friends...?
10. What does camp mean to you?
  - a. A place to...?
11. What have you learned about yourself here?
12. Do you think camp has changed you?
  - a. If so, in what ways? If not, why not?
  - b. When you go home, do you plan to do anything differently in your “real life?”
13. Is there anything else that you want to share?

***Thank You!***

**B. 2-3 Year Campers; 4+ Year Campers**

1. How long have you attended this camp?
2. Do you do things with the people from this camp outside of camp?
  - a. What?
3. Why do you come to camp?
4. What do you think the goals of Camp For All are?
  - a. Why do you think (insert partner agency) works with Camp For All?
5. What do you like most about camp?
6. What don't you like, or what would you change about camp?
7. What are the staff like?
8. What are the activities like?
9. Have you done anything new here?
10. What have you learned about yourself here?
11. What does camp mean to you?
  - a. A place to...?
  - b. Has that changed since you first started attending?
12. What have you learned about yourself since first coming here?
13. Do you think camp has changed you?
  - a. If so, in what ways? If not, why not?
  - b. When you go home, do you plan to do anything differently in your “real life?”
14. Is there anything else that you want to share?

***Thank You!***



## APPENDIX D

## CONSENT FORMS FOR CAMPERS AND ADULTS

(2008)

**Program Evaluation of the Camp For All Program:  
Parent/Guardian Permission Form  
Texas A&M University**

The following are characteristics of the study:

- ❖ Your child has been asked to participate in a research study examining outcomes of camp on campers. Your child was selected to be a participant because your child registered to attend Camp SIA, Camp that Love Built, Camp Spike 'n' Wave, Camp Hope, or Camp Periwinkle at the Camp For All site in Burton, Texas during the summer of 2008.
- ❖ All campers are being asked to be in this study. Study participants will be asked to complete surveys that ask questions about their experiences at camp. One of these surveys will be mailed to you following camp. Study participants may also take part in a focus group that asks them specific questions about how camp went for them.
- ❖ The purpose of this study is to identify how camp impacts campers, and how participating in camp impacts campers.
- ❖ Your child could experience discomfort if she/ he is sensitive about the questions. However, there are no other apparent risks to your child's participation in this study. While there are no direct benefits to your child, your child's involvement will be useful for improving Camp For All and its partner agencies, and for documenting the effectiveness of the camp for youth.
- ❖ All information collected during this study will be confidential. Your child will be asked to write his or her name and address on the front sheet of the survey packet to enable data collection in future years at camp. Only the project team staff will be able to link your child's name and address to his or her responses. The research records of your child's responses will be kept private. None of your child's identifying information will be referenced in any sort of report that might be published. Research records will be stored securely, and only evaluation project team staff (Dr. Clifton Watts and 2 graduate students from Texas A&M) will have access to the records. Your child will not have to answer any questions that your child doesn't want to answer. If your child chooses not to complete the survey, your child will not receive any penalties or be punished in any way and will still take part in all camp activities.
- ❖ By law, we must report to the state suspected cases of child abuse, or if your child tells us that he/she is planning to do serious harm to him/herself or others. The questions asked during the interviews do not collect information regarding child abuse, sexual assault, or the illegal activities of others. To further protect your child, he/she will be instructed not to mention anybody's last name during the survey.
- ❖ Whether you allow your child to participate or not, this decision will not affect your child's current or future relationships with Texas A&M University, Camp For All, Camp SIA, Camp that Love Built, Camp Spike 'n' Wave, Camp Hope, or Camp Periwinkle. Your child is free to withdraw from the study described above without concern at any time.
- ❖ Your child and you can contact Clifton Watts at Texas A&M University by phone at 979-862-4373 (or his cell 979-204-5275), or by email at [cwatts@tamu.edu](mailto:cwatts@tamu.edu), or by mail at Francis Hall, 2261 TAMU, Texas A&M University, College Station, TX 77843-2261 with any questions about this study. This research study has been reviewed by the Institutional Review Board - Human Subjects in Research, Texas A&M University. For research-related problems or questions regarding subjects' rights, you can contact the Institutional Review Board through Ms. Melissa McIlhaney, IRB Program Coordinator, Office of Research Compliance, (979)458-4067, [mcihaney@tamu.edu](mailto:mcihaney@tamu.edu).

- ❖ Please be sure you have read the above information, asked questions and received answers to your satisfaction. You will be given a copy of the consent form for your records. By signing this document, you give your consent for your child to participate in the study.

Written Name of Parent/ Guardian: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Parent/ Guardian: \_\_\_\_\_

Name of Child: \_\_\_\_\_

Address of Child: \_\_\_\_\_  
Street Address

\_\_\_\_\_  
City

\_\_\_\_\_  
State

\_\_\_\_\_  
Zip code

**Needs Assessment of the Camp For All Program:  
Camp Administrator and Staff Form  
Texas A&M University**

- ❖ You have been asked to participate in a research study examining outcomes of camp on campers. You were selected to be a participant because you are a camp administrator or camp staff member for Camp For All (CFA), Camp Spike 'n' Wave, Camp Hope, Camp Periwinkle, or Muscular Dystrophy Association Camp, at the Camp For All site in Burton, Texas during the summer of 2008.
- ❖ All administrators and staff associated with the above camps are being asked to be in this study. Approximately 5 administrators and camp staff members will be chosen and asked to participate in in-depth interviews. Interviews will take 20-30 minutes, and will take place by phone or at camp, depending on the camp schedule, at a time convenient for you.
- ❖ The purpose of this research is to perform an outcomes assessment that attempts to understand outcomes for campers that are associated with participation at CFA as part of a three-year evaluation of the program. The long-term evaluation strategy will employ a comprehensive assessment of processes and outcomes. This evaluation can inform CFA's key stakeholders—its clients, program personnel, administration, and funding partners.
- ❖ You will be asked to 1) verbally answer interview questions, and; 2) have your answers audio taped. The interviews will last 20-30 minutes.
- ❖ You could experience discomfort if you are sensitive about the questions. However, there are no other apparent risks to your participation in this study. While there are no direct benefits to you, your involvement will be useful for improving Camp For All and its partner agencies, and for documenting the effectiveness of the camp for youth.
- ❖ All information collected during this study will be confidential. The research records of your audio taped responses will be kept private. None of your identifying information will be referenced in any sort of report that might be published. Research records will be stored securely, and only evaluation project team staff (Dr. Clifton Watts and 3 graduate students from Texas A&M) will have access to the records. You will not have to answer any questions that you don't want to answer. If you choose not to complete the interview, you will not receive any penalties or be punished in any way.

- ❖ By law, we must report to the state suspected cases of child abuse, or if you tell us that a child said that he/she is planning to do serious harm to him/herself or others. The questions asked during the interviews do not collect information regarding child abuse, sexual assault, or the illegal activities of others. To further protect you, you will be instructed not to mention anybody's last name during the interview.
- ❖ Whether you decide to participate or not, this decision will not affect your current or future relationships with Texas A&M University, Camp For All, Camp Spike 'n' Wave, Camp Hope, Camp Periwinkle, or Muscular Dystrophy Association Camp. You are free to withdraw from the study described above without concern at any time.
- ❖ You may be contacted for a follow-up call to verify information shared in your interview. If you are contacted, you may choose to decline the follow-up if you choose. Again, your decision whether or not to participate in this follow-up will not affect your relationships with any of the organizations listed above.
- ❖ Your child and you can contact Clifton Watts at Texas A&M University by phone at 979-862-4373, or by email at [cwatts@tamu.edu](mailto:cwatts@tamu.edu), or by mail at Francis Hall, 2261 TAMU, Texas A&M University, College Station, TX 77843-2261 with any questions about this study. This research study has been reviewed by the Institutional Review Board - Human Subjects in Research, Texas A&M University. For research-related problems or questions regarding subjects' rights, you can contact the Institutional Review Board through Ms. Melissa McIlhaney, IRB Program Coordinator, Office of Research Compliance, (979)458-4067, [mcilhaney@tamu.edu](mailto:mcilhaney@tamu.edu).
- ❖ Please be sure you have read the above information, asked questions and received answers to your satisfaction. You will be given a copy of the consent form for your records. By signing this document, you give your consent to participate in the study.

Written Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

## APPENDIX E

### ASSENT PROCEDURE AND INTERVIEW QUESTIONS

(2008)

#### **Interview Guide – Camp Staff**

Hi, my name is Ann Gillard and I am here because Camp For All and Camp Hope are doing a research study on what camp does for campers, and want to get the perspectives of the camp staff along with campers and parents/ caregivers.

I'm trying to find out about the role that camp plays in kids' lives. From last summer's study, we identified some outcomes associated with going to camp. This year, I want to get more in-depth information about outcomes, and to try to connect these outcomes to processes that happen within the camp experience.

There are no right or wrong answers – I'm interested in what you think. The interview should take about 15-20 minutes, and will be tape recorded.

In the interview, I will ask you some questions about your perspective of the outcomes of camp for campers, and what within camp might influence those outcomes. All of your answers would be totally confidential, and none of your answers would ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, you can be totally honest and open with me – I really want to know what you think so that we can improve camp for other kids. And, don't worry that anything you say here will get back to the camp director, counselors or other staff, other campers, or anyone else. Even if you decide not to participate in the interview at all, there will be no bad effects for you. If you have any questions or concerns about this study, I can provide you with people's names and numbers to contact.

Do you have any questions? Do you agree to participate in the study? [give consent form]

So that I don't have to spend a lot of time writing everything down, and instead be able to listen to what you're saying, is it ok with you if I tape record our interview? Do you have any questions before we start?

### **Interview Guide – Camp Staff**

1. What are the goals of camp?
  - a. Do you feel you are meeting these?
2. What goals and outcomes do you want to happen for campers?
  - a. What messages do you want to send to campers?
3. How do you think camp contributes to the positive development of kids?
  - a. What could be better?
4. What is your understanding of positive youth development?
5. How does it get accomplished at camp?
6. What is your role in making the goals and outcomes for this camp happen?
7. What sort of training do you get in order to prepare you to work with campers in developmentally positive ways?
8. Do you think your views match your camp director's views on what is "developmentally positive"?
9. Is there anything else that you would like to share?

### **Interview Guide – Campers**

Hi, thanks for taking time away from the activities to help me with this research project that I'm doing. My name is Ann Gillard and as part of my job I look at camps like Camp Hope to find out more about them. Some of you may remember me from last summer when some other students and I came in to camp to do focus groups with some campers. This time we're going to talk with you one-on-one.

We're trying to find out what you think about camp, and what it means to you in your life. A lot of times, people think they know what camp is all about, but we want to get YOUR opinion on it. There are no right or wrong answers – we're interested in YOUR experiences.

I'm going to ask you some questions about your experiences at camp and at home, and this should take around 20-30 minutes. All of your answers are totally confidential, which means that none of your answers will ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, please feel free to be totally honest and open with me – we really want to know what you think so that we can improve camp for other folks like you. And, don't worry that anything you say here will get back to your counselors or other staff, other campers, your family, or anyone else – I promise that what is said here, stays here.

So that I don't have to spend a lot of time writing everything down, and instead be able to listen to what you're saying, is it ok with you if I tape record our interview? Do you have any questions before we start?

[Get assent]

### CAMPER INTERVIEW QUESTIONS

1. What were the most memorable experiences from camp?
  - a. Why were these experiences memorable?
  - b. What do these experiences mean to you as you move forward in your life?
2. Complete this sentence: Camp is a place where I...
  - a. What do you mean by that statement?
3. If you had to say 3 things that made camp special to you, what would they be?
4. How does camp let you “be you”? (Or does it?)
5. How does camp help you grow as a young person differently than other important areas in your life (school, family, church, etc.)?
6. How are your relationships with other campers?
  - a. What do camp friendships mean to you?
7. Do you see these folks after camp/maintain friendships?
  - a. If so, what do you do with them?
8. How are your friends at camp different from your friends at home?
9. What are your relationships like with the counselors at camp?
  - a. In general, how do you feel about your counselors?
  - b. What stands out in your mind about these counselors?
  - c. If you could be like one of your counselors, who would it be? Why?
10. Compare camp to other parts of your daily life - how are they similar and different from each other?
  - a. In what ways is camp the same or different than your life at home?
11. Think about when you return home from camp, how do you feel?
  - a. What do you tell your family and friends about camp when you return home?
  - b. What parts of camp stay with you when you are back home?
12. If another kid with (illness) was thinking about coming to this camp, what would you tell them?
13. Are you planning to go back to camp?
  - a. What are you looking forward to/ nervous about?
  - b. If not returning to camp, why not?
14. Is there anything else you'd like to share?

Thank you for your time – I greatly appreciate it!

### **Interview Guide – Administrator**

Hi, my name is Ann Gillard and I am here because I am doing a research study on what camp does for campers, and want to get the perspectives of you as the camp director, along with those of campers, parents/ caregivers, and camp staff

I'm trying to find out about the role that camp plays in kids' lives. From last summer's study, we identified some outcomes associated with going to camp. This year, I want to get more in-depth information about outcomes, and to try to connect these outcomes to processes that happen within the camp experience.

There are no right or wrong answers – I'm interested in what you think. The interview should take about 15-20 minutes, and will be tape recorded.

In the interview, I will ask you some questions about your perspective of the outcomes of camp for campers, and what within camp might influence those outcomes. All of your answers would be totally confidential, and none of your answers would ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, you can be totally honest and open with me – I really want to know what you think so that we can improve camp for other kids. And, don't worry that anything you say here will get back to your agency, counselors or other staff, other campers, or anyone else. Even if you decide not to participate in the interview at all, there will be no bad effects for you or Camp Hope. If you have any questions or concerns about this study, I can provide you with people's names and numbers to contact.

Do you have any questions? Do you agree to participate in the study? [give consent form]

So that I don't have to spend a lot of time writing everything down, and instead be able to listen to what you're saying, is it ok with you if I tape record our interview? Do you have any questions before we start?



### **Interview Guide – Camp Administrator**

1. What are your goals and expectations for adding to the positive development of your campers?
2. What are the goals that your organization is trying to achieve for campers?
3. What do you do with staff to prepare them to work with campers in developmentally positive ways?
4. Do you think your views match your staff's views on this?
5. What messages do you want staff to send to campers?
6. Is there anything else you'd like to share?

## APPENDIX F

## REVISED CAMPER INTERVIEW QUESTIONS

(2008)

**INTERVIEW QUESTIONS (revised for Camp Hope)**

1. What were the most memorable experiences from camp?
  - a. Why were these experiences memorable?
  - b. What do these experiences mean to you as you move forward in your life?
2. Complete this sentence: Camp is a place where I...
  - a. What do you mean by that statement?
3. If you had to say 3 things that made camp special to you, what would they be?
4. How does camp let you “be you”? (Or does it?)
5. How does camp help you grow as a young person differently than other important areas in your life (school, family, church, etc.)?
6. How are your relationships with other campers?
  - a. What do camp friendships mean to you?
7. Do you see these folks after camp/maintain friendships?
  - a. If so, what do you do with them?
8. How are your friends at camp different from your friends at home?
  - a. *Would you say you were very open, very closed, or both open and closed about sharing personal information or feelings with people?*
9. What are your relationships like with the counselors at camp?
  - a. In general, how do you feel about your counselors?
  - b. What stands out in your mind about these counselors?
  - c. If you could be like one of your counselors, who would it be? Why?
10. *Compare camp to other parts of your daily life - how are they similar and different from each other?*
  - a. *In what ways is camp the same or different than your life at home?*
11. *Are you involved in any educational, support, or public speaking programs at home?*
  - a. *Why or why not? If so, what do you get out of it?*
  - b. *Is that something you might want to do someday?*
  - c. *Why or why not? If so, what do you think you would get out of it?*
12. Think about when you return home from camp, how do you feel?
  - a. What do you tell your family and friends about camp when you return home?
  - b. What parts of camp stay with you when you are back home?

13. If another kid with (illness) was thinking about coming to this camp, what would you tell them?
14. Are you planning to go back to camp?
  - a. What are you looking forward to/ nervous about?
  - b. If not returning to camp, why not?
15. Is there anything else you'd like to share?

Thank you for your time – I greatly appreciate it!

APPENDIX G  
CAREGIVER INTERVIEW GUIDE

(2008)

**Interview Guide – Parents/ Caregivers**

Hi, my name is Ann Gillard and I am here because I am doing a research study on what camp does for campers. We are talking with the parents and caregivers of campers who attended Camp Hope in the past. You were recommended by the camp director of Camp Hope as someone who might have some useful insight about what camp has done for your child.

Last summer I talked to campers and camp staff to find out about what camp does for campers. Now I'm trying to find out more about what camp does for kids from the perspective of parents and caregivers of campers.

A lot of times, people think they know what camp is all about, but I want to get YOUR opinion on it. There are no right or wrong answers – I'm interested in what you think. The interview should take about 15-20 minutes, and would be tape recorded.

In the interview, I will ask you some questions about your child's experiences at camp and at home. All of your answers would be totally confidential, and none of your answers would ever be connected to your name. You can choose to not answer any question if you want, and you can stop the interview at any time. Also, you can be totally honest and open with me – I really want to know what you think so that we can improve camp for other kids like yours. And, don't worry that anything you say here will get back to the camp director, counselors or other staff, other campers, your child, or anyone else. Even if you decide not to participate in the interview at all, there will be no bad effects for you or your child. If you have any questions or concerns about this study, I can provide you with people's names and numbers to contact.

Do you have any questions? Do you agree to participate in the study? [give consent form]

So that I don't have to spend a lot of time writing everything down, and instead be able to listen to what you're saying, is it ok with you if I tape record our interview? Do you have any questions before we start?

### Interview Guide – Parents/ Caregivers

1. Why do you send your child to camp?
2. Describe what it's like when your child returns home from camp:
  - a. What impression do they give about camp?
  - b. What words do they use to describe camp?
  - c. What types of feelings do they convey to you about camp?
  - d. How do they talk about other campers?
  - e. The counselors?
  - f. Do these relationships extend after camp? How?
3. What do you think happened WITHIN camp that affected your child in the ways you just shared?
  - a. How did your child describe her/his interactions with counselors, other campers, the activities?
4. How do you think camp affects/influences your child when they return home?
  - a. What things from camp most affect your child's daily life?
  - b. What 2 things stand out the most in your mind about the value of the camp experience for the growth of your child?
  - c. What would you like to change about that experience for your child?
5. How are your child's friends at camp different from their friends at home?
  - a. Would you say she/he is very open, very closed, or both open and closed about sharing her/his personal information or feelings with you? Other kids? Other adults??
6. On a daily basis, what is your child's life like at home?
  - a. What are the most significant relationships in your child's life?
  - b. What issues do they face - with illness, other kids, family, life experiences?
  - c. What types of things do they typically do after-school?
  - d. What sorts of things do they do with you?
  - e. With friends?
  - f. What are the important life interactions that occur for your child?
7. If another parent or caregiver was hesitant to send their child to camp, what advice would you give them?
8. Is there anything else that you would like to share?

APPENDIX H  
REVISED AND MAILED CAREGIVER QUESTIONNAIRE  
(2008)

August 1, 2008

Dear Camp Hope Parents and Caregivers,

We are writing to ask for your help with a study we are doing about the role of Camp Hope in children's lives. In order to do a good job with the study, we are contacting parents and caregivers of children who have attended Camp Hope to ask for their input. You were specifically recommended by Marc Cohen (the camp director of Camp Hope) as someone who could provide useful views about what camp has done for your child.

This summer and last summer I talked with campers and camp staff to find out what camp does for campers (following appropriate procedures for consent and confidentiality). Now we are trying to find out more about what camp does for kids from the point of view of parents and caregivers. Attached is a survey that asks about your child's experiences at camp and at home.

All of your answers are totally confidential, and none of your answers will be connected to your name. All identifying information will be destroyed once we receive your survey. You can choose to skip any question you want. Nothing you share will ever get back to the camp director, counselors or other staff, other campers, your child, or anyone else. Even if you decide not to do the survey at all, there will be no negative results for you or your child.

We hope you will be totally honest and open on the survey – we really want to know what you think! While there is no direct benefit to you for participating, your help will enable us to improve camp for your child or other kids who might attend Camp Hope in the future.

If you decide to do the survey, please fill out the attached survey and send it back to us in the postage-paid envelope **by August 15, 2008**, or you can email your answers if you wish to Ann Gillard at [agillard@tamu.edu](mailto:agillard@tamu.edu).

If you have questions about this study, please contact Ann at [agillard@tamu.edu](mailto:agillard@tamu.edu) or by phone at 979-450-4264.

This research study has been reviewed by the Institutional Review Board - Human Subjects in Research, Texas A&M University. For research-related problems or questions regarding subjects' rights, you can contact the Institutional Review Board

through Ms. Melissa McIlhaney, IRB Program Coordinator, Office of Research Compliance, (979) 458-4067, [mcilhaney@tamu.edu](mailto:mcilhaney@tamu.edu).

Thank you!

Ann Gillard and Peter Witt

### **Camp Hope Parent and Caregiver Survey**

Please provide as much information as you can in response to the questions. If there is not enough space, please write additional information on the back of the page. It should take you from 10-15 minutes to answer the questions.

1. Why do you send your child to camp?
2. Describe what it's like when your child returns home from camp:
  - a. What do they say about camp?
  - b. What types of feelings do they have about camp?
  - c. What do they say about other campers?
  - d. What do they say about the counselors?
  - e. Do they keep in touch with camp friends after camp? If yes, how?
3. What do you think happened WITHIN or AT camp that affected your child in the ways you shared in Question 2?
4. How do you think camp affects or influences your child when they return home?
  - a. What things from camp most affect your child's daily life?
  - b. What 2 things stand out the most in your mind about the value of the camp experience for the growth of your child?
  - c. What would you like to change about the camp experience for your child?
5. If another parent or caregiver was unsure about sending their child to camp, what advice would you give them?
6. Is there anything else that you would like to share?

APPENDIX I  
ARTIFACT LIST  
(2008)

Artifact List – Camp Hope

1. Camp Hope memory book
2. 3 CH t-shirts
3. 3 gift bags given to girls by Olivia and her friends (girls wrote 18 thank you cards) – contained earrings, notebooks, hair ties, etc.
4. Camp Hope rock from X – in pouch, with inspirational message about “Touchstones”
5. My nametag
6. Red star visor
7. Strawberry bandana
8. Southwest airlines pen
9. Southwest airlines keychain
10. Southwest airlines baseball hat
11. Camp Hope Olympics medal
12. CFA map
13. Camp Hope counselor manual
14. Handouts from counselor training
15. Camper lists
16. Camp Hope schedule
17. Binder of emails about Camp Hope



## APPENDIX J

## CAMP HOPE EMAIL EXAMPLES

(2008)

June 23, 2008

From Camp Director to Counselors:

Thanks to all for attending orientation on Saturday. I will be sending some info out in the next day or so, decided to take this afternoon off to play catch up prior to camp. Did receive this question from one of y'all so figured I would share both the question and the answer

How will showers for counselor and campers work? Separate quarters, separate times? Will the campers go at specific times, by age? I hope we have separate showers but at a minimum different times slotted for us. I understand there will be separate male/female showers.

The front section of each cabin consist of 14 beds - 2 sets of bunk beds and then (10) twin beds. The back section has three each - sinks, commodes and shower stalls. These are used for both the campers and counselors placed in the cabin. Typically the counselors will wake up early take their showers and get dress prior to waking up the kids. The cabins also have a rather large storage closet that some counselors have used to place their personal belonging in and also use as a changing area. None of the cabins are co-ed.

Both the shower stalls and commodes have curtains separating them rather than doors that can be latched. The commodes in the dinning room , arts & crafts area, health center and out at horses are more private with solid wood sides and doors that latch.

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July 10, 2008

From Camp Director to Counselors:

**Hope everyone is getting some rest –  
we are 10 days away from the  
beginning of Camp Hope 2008**

Allonna and I are wrapping up the last details for this year's camp . We have had some kids back out and some that have been added in, the attached list is the most up to date list. If you still are in need of a ride to camp, please contact Allonna so she might assist you with finding one – jamesa@afhouston.org

1. as you gather up your cabin decorations we budget \$50 per cabin for those. Please give me your receipts and we will generate reimbursement checks for you.
2. you need to be onsite at Camp For All by 4 pm on Saturday, July 19. I have spoken to a few of you who have made other arrangements with me. The soonest you will be able to arrive is 2 pm.
  - a. Pull into the circular drive and temporarily park your car
  - b. As you walk into the dinning room, there will be a table that will have both your cabin name tag and also your luggage tags
  - c. You will be able to tag your luggage and place next to the appropriate cabin # sign – CFA will take your luggage to your cabin if you wish
  - d. Move your car to the surface lot
  - e. Please collect your cabin bags – t—shirt and information bag & toiletry bag. They will be in numerical order on the stage. As well as you cabin rules. CFA will bring down your cabin box
3. we will begin our onsite orientation at 5:30 pm in the dinning room
4. we will have a hot week so please pack accordingly.

**Sunday, Jul 20**

**High: 89 °F RealFeel®: 93 °F**

Intervals of clouds and sunshine

**Sunday Night, Jul 20**

**Low: 69 °F RealFeel®: 75 °F**

Partly cloudy

**Monday, Jul 21**

**High: 89 °F RealFeel®: 93 °F**

Mainly cloudy

**Monday Night, Jul 21**

**Low: 68 °F RealFeel®: 76 °F**

Rather cloudy

**Tuesday, Jul 22**

**High: 92 °F RealFeel®: 99 °F**

Humid with periods of clouds and sunshine

**Tuesday Night, Jul 22**

**Low: 72 °F RealFeel®: 78 °F**

Partly cloudy

**Wednesday, Jul 23**  
**High: 96 °F RealFeel®: 100 °F**  
 Mostly sunny  
**Wednesday Night, Jul 23**  
**Low: 71 °F RealFeel®: 78 °F**  
 Mainly clear  
**Thursday, Jul 24**  
**High: 96 °F RealFeel®: 100 °F**  
 Mostly sunny  
**Thursday Night, Jul 24**  
**Low: 71 °F RealFeel®: 77 °F**  
 Mainly clear

Let me know if you need anything .....see everyone at camp !

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July 10, 2008

From Camp Director to Psychosocial and Medical staff members:

Just a reminder that we will be meeting on Tuesday – July 15 @ 2 pm, in the Retro area of TCH – Clinical Care building on the 12<sup>th</sup> floor. For the out of town groups please forward to me a # which you would like for me to call you at.

This will be the only time we will come together prior to camp to go over a few things so I hope everyone will be able to make time to participant. Listed below is what we will cover

- By group any concerns either behaviorally or medically about your campers ( see attached camper list by user group )
- Teen Talk and Tween Talk programs ( see attached Teen Talk schedule )
- Behavioral staffing at camp
- New additions to camp schedule ( see attached schedule )

*Dallas, Ft Worth, Florida – you name tags and luggage tags will be Fed Ex to you on Friday for a Monday delivery. Please review and if there are any changes that need to be made please let me know. For the folks who will not be travelling on the bus to camp their tags will be collect at camp when they arrive.*

As always thanks to each of you for your help with Camp.

August 20, 2008

From Camp Director to Counselors and others associated with Camp Hope:

Hello All, wanted to touch base in regards to camper / counselor communication outside of Camp Hope. As each of you know, we (AFH ) take the privacy of both our campers and counselors very seriously. Because of this we do not allow any exchange of personal contact information between the campers and counselors – phone numbers, e-mail addresses, physical addresses. Campers who would like to maintain a relationship with a counselor outside of camp must have their caregiver contact us authoring that. At that point I would contact the counselor to determine if they (the counselor) wish to have such contact.

The reason I bring this up, is that recently I received a call from a counselor who had been asked to be a friend on face book of a person they did not know. They agreed to this, however they then determine the person was a good friend of one of our campers. At that point they declined the invitation to be friends on face book. To my understanding face book is a form of social networking using the internet. Persons are able to view very personal information and also use it as a form of communication.

Since this is a form of communication, please know that the camper / counselor communication policy applies to both face book and my space accounts. If you should be approached on either one of these internet groups to be a friend of a camper we are asking that you decline that invitation. In addition, if you are asked to be a friend by a total stranger on either of these and agree, once you realize that person has any form of a relationship with one our campers then you must remove yourself from being a friend on face book / my space with them .

## VITA

**Ann Gillard****TAMU 2261, College Station, TX 77843-2261****anngillard@gmail.com, 979-450-4264**

## EDUCATION

*Texas A&M University*, College Station, TX (8/05-12/08). Ph.D. Youth Development.  
 Thesis: "At Home, I'm Clark Kent. At Camp, I'm Superman." Outcomes and Processes  
 of a Camp for Youth with HIV/AIDS.

*San Francisco State University*, San Francisco, CA (9/03-5/05). M.S. in Recreation and  
 Leisure Management, 2005

*Indiana University*, Bloomington, IN (9/94-12/96). B.S. in Outdoor Recreation and  
 Natural Resource Management, 1996

*DePaul University*, Chicago, IL (9/92-6/94) Communications.

## EXPERIENCE

*Research and Teaching Assistant; Instructor*. Texas A&M University (8/05-12/08)

*Camp Director*. Girl Scouts of San Francisco Bay Area, Fairfax, CA (02/05-08/05)

*Teacher*. John Muir Charter School, San Francisco, CA (part time, 10/04-05/05)

*High School Leadership/ Environmental Internship Program Manager*. San Francisco  
 Conservation Corps, San Francisco, CA (09/03-10/04)

*Program Manager/ Camp Director*. Girl Scouts of Southeastern Pennsylvania,  
 Philadelphia, PA (11/99-08/03); Assistant Camp Director (summer, 2006)

*Youthworker/ Community Extension Coordinator*. Tulip Trace Council of Girl Scouts,  
 Bloomington, IN (11/97-11/99)